From Eugenics to Public Health Genetics in Mid-Twentieth Century Minnesota

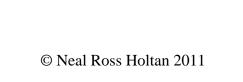
# A DISSERTATION SUBMITTED TO THE FACULTY OF THE GRADUATE SCHOOL OF THE UNIVERSITY OF MINNESOTA BY

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# **Dedication**

This dissertation is dedicated to Stephen Mark Dent, my partner in all things, who has steadfastly supported my long quest to reach this goal.

#### **Abstract**

In the twentieth century, people in Minnesota experienced four developmental phases of human genetics in distinct organizational manifestations: the Minnesota Eugenics Society (organized in 1926), the Dight Institute for Human Genetics at the University of Minnesota (established in 1941), the Minnesota Human Genetics League (incorporated in 1945), and the Human Genetics Unit at the Minnesota Department of Health (authorized in 1959 and created in 1960). The first three phases are tied to the last, the unprecedented establishment of public health genetics that made Minnesota the first state to organize a public human genetics program. I examine the intellectual, scientific, and social roots of public health genetics and its relationship to the rest of public health practice before reaching the conclusion that the promise of public health genetics appeared to have been high for its proponents in the beginning, but because of the sociocultural shifts of values in the 1970s and a poor fit with public health's traditional array of strategies, it did not thrive over time.

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#### CHAPTER 1

#### **Introduction: Public Health Genetics in Minnesota**

Only a momentary descent from our academic towers is necessary to discover the popular interest in the subject of heredity and its social implications, and the desire for some sort of action in the field for the benefit of everyone.<sup>1</sup>
—Sheldon C. Reed (1959)

# **Something Entirely New**

The exact starting date for a specialty of science, medicine, or public health is rarely, if ever, known. The best approximation for the establishment of most fields of science is the date when its new practitioners organize themselves as a professional association and begin to interact as a self-defined group. The practice of public health genetics, the application of genetic science to benefit the health of human populations, emerged from a variety of roots and antecedents in human genetics, but it perhaps can be more precisely dated than other fields because it came into existence as an organizational structure through an act of the Minnesota legislature signed by the governor on April 24, 1959, and first took institutional shape at the Minnesota Department of Health as the Human Genetics Unit in the year 1960.

Although suddenly new, the field of public health genetics tapped into intellectual, scientific, and academic roots in Minnesota and elsewhere. Those broad antecedents included the practice of public health, the science of human genetics, advocacy for birth control and reproductive rights, and the earlier Progressive and eugenics movements, all with overlapping and interwoven histories themselves.

<sup>&</sup>lt;sup>1</sup> Sheldon C. Reed, Dight Institute *Bulletin no. 11*, (1959).

Few historians have concentrated on public health genetics exclusively. Martin S. Pernick has analyzed the relationship between eugenics and public health in the early twentieth century. Diane B. Paul has written extensively about the social, cultural, and political aspects of eugenics and human genetics.<sup>3</sup> Paul and other historians, namely Ruth Schwartz Cowan and M. Susan Lindee, have studied particular components of public health genetics such as mass screening for genetic diseases in newborns and the public policy implications of genetic counseling.<sup>4</sup> No one, however, has examined the subject of the present study, the establishment of a public health genetics program in a state health department and the application of genetic science to populations in the 1960s. This study builds on the work of Pernick, Paul, Lindee, and others to connect human genetics with the field of public health and to understand the social and cultural context of attempts to improve and control heredity. Pernick's focus on eugenics and public health and Paul's emphasis on socio-cultural aspects of human genetics point the way to understanding the abrupt rise and the rapid contraction of public health genetics in mid-twentieth century Minnesota. This dissertation addresses two sets of developments: first, the intellectual, scientific, academic roots and necessary conditions for public health genetics to have come into existence; and second, the relationship of public health genetics to the traditional functions and practice of public health.

<sup>&</sup>lt;sup>2</sup> Martin S. Pernick, "Eugenics and Public Health in American History," *American Journal of Public Health* 87 (1997): 1767–72.

<sup>&</sup>lt;sup>3</sup> Diane B. Paul, *The Politics of Heredity: Essays on Eugenics, Biomedicine, and the Nature–Nurture Debate* (Albany, NY: The State University of New York Press, 1998).

<sup>&</sup>lt;sup>4</sup> Diane B. Paul, *Controlling Human Heredity: 1865 to the Present* (Amherst NY: Humanity Books, 1998); Ruth Schwartz Cowan, *Heredity and Hope: The Case for Genetic Screening* (Boston, MA: Harvard University Press, 2008); M. Susan Lindee, *Moments of Truth in Genetic Medicine* (Baltimore, MD: The Johns Hopkins University Press, 2005).

#### **Human Genetics**

Genetics, "the study of heredity and the variation of inherited characteristics," scarcely existed as a scientific field of knowledge before 1900.<sup>5</sup> The rediscovery that year of Gregor Mendel's (1822–1884) 36-year-old paper describing his breeding experiments on garden peas sparked an explosion of interest in heredity. Scientists discovered information about the inherited characteristics of plants and animals and figured out the roles that cellular structures played in transmitting biological inheritance.<sup>6</sup>

Human genetics was the last component of the field of genetics to develop, roughly from 1930 to 1980.<sup>7</sup> Geneticists had been reluctant to study humans because of their biological complexity and inappropriateness for breeding experiments. With such doubts surrounding them, academic geneticists who had been trained in plant and animal genetics faced a risk in committing their careers to the uncertain prospects of human genetics. But, as scientific knowledge about genetics accumulated, a few made the shift in the early 1940s and began to identify themselves as human geneticists. Sixty

<sup>&</sup>lt;sup>5</sup> Oxford Dictionaries, English Dictionary and Reference, http://www.oxforddictionaries.com/view/entry/m\_en\_us1250477#m\_en\_us1250477, accessed February 28, 2011.

<sup>&</sup>lt;sup>6</sup> For a concise first-hand account of the history of genetics, see Alfred H. Sturtevant, *A History of Genetics* (New York, NY: Harper & Row, 1965), reprinted (Cold Spring Harbor, NY: Cold Spring Harbor Laboratory Press and Electronic Scholarly Publishing Project, 2001); for an in-depth history of genetics, see James Schwartz, *In Pursuit of the Gene: From Darwin to DNA* (Cambridge. MA: Harvard University Press, 2008); for a social history of genetics, see Kenneth M. Ludmerer, *Genetics and American Society: A Historical Appraisal* (Baltimore, MD: The Johns Hopkins University Press, 1972).

<sup>&</sup>lt;sup>7</sup> Peter S. Harper, *A Short History of Medical Genetics* (New York, NY: Oxford University Press, 2008); 240-45; for a different range of time for the development of human genetics, 1955–1975, see M. Susan Lindee, *Moments of Truth in Genetic Medicine* (Baltimore, MD: The Johns Hopkins University Press, 2005): 1; see also Ludmerer, "Reconstruction of Human Genetics," *Genetics and American Society*, 165–202.

geneticists met for the inaugural meeting of the American Society of Human Genetics in 1948  $^8$ 

I argue that human genetics in Minnesota had four distinct and roughly chronological manifestations, namely, eugenics, academic human genetics, public advocacy for human genetics, and public health genetics. Each iteration assumed a particular organizational structure: the Minnesota Eugenics Society (organized in 1926), the Dight Institute for Human Genetics at the University of Minnesota (established in 1941), the Minnesota Human Genetics League (incorporated in 1945), and the Human Genetics Unit at the Minnesota Department of Health (authorized in 1959 and created in 1960). The first three stages of human genetics were connected with each other and had significance for the eventual rise and fall of the public health genetics program in Minnesota. I relate their histories and analyze them in the four chapters that follow. The last chapter considers the historical meaning of the public health genetics phenomenon, examines its expansion and contraction as a specialty of public health, and draws conclusions about its role in preventing hereditary diseases in the population.

### **Repackaging Eugenics**

Prior to 1940, it was eugenicists who tried to apply genetic knowledge to improve the hereditary quality of populations. Eugenics was a movement in the early twentieth century to encourage individuals with desirable hereditary traits to reproduce and to discourage or prevent those deemed to have undesirable traits from having offspring.

With sketchy scientific understanding of human genetics, many proponents of eugenics

<sup>&</sup>lt;sup>8</sup> Herluf H. Strandskov, handwritten journal and scrapbook, Papers of the American Society of Human Genetics, American Philosophical Society.

simply extrapolated Mendel's laws of inheritance in garden peas not only to physical human characteristics but also to complex behaviors such as criminality, alcoholism, and feeble-mindedness. Eugenicists used Mendelian genetics as the basis for legitimizing interventions aimed at preventing the hereditary perpetuation of physical characteristics and other conditions that they perceived as undesirable and inheritable. For example, eugenicists created laws in many states for the institutionalization and surgical sterilization of the so-called feeble-minded to prevent them from degrading the gene pool. More than 50,000 individuals in the United States were sterilized for eugenic reasons during the first half of the twentieth century. In

Abhorrence of the harsh eugenic and racial policies of Nazi Germany during the 1930s and 1940s, modeled in part on some of the earlier eugenic sterilization and marriage laws in the United States, seemingly put an end to eugenics as legitimate social policy after World War II. Most people considered eugenics to be a dead movement, but historian Alexandra Stern has argued that it was instead being "repackaged," with individual choice and private decision-making replacing government coercion, at least in theory. The first new package, dubbed *genetic counseling* in 1948, entailed the medical application of human genetic science in the care of patients and their families. Its creators held firmly to the principle of consent for patients receiving genetic counseling instead of

<sup>&</sup>lt;sup>9</sup> Throughout this dissertation, I use terminology, such as that for mental disabilities, consistent with the time, rather than terms that evolved later.

<sup>&</sup>lt;sup>10</sup> Mark A. Largent, Breeding Contempt: The History of Coerced Sterilization in the United States (New Brunswick, NJ: Rutgers University Press, 2008).

<sup>&</sup>lt;sup>11</sup> Daniel J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (Cambridge, MA: Harvard University Press, 1985), new edition 1995.

<sup>&</sup>lt;sup>12</sup> Alexandra Minna Stern, *Eugenic Nation: Faults and Frontiers of Better Breeding in Modern America* (Berkeley, CA: University of California Press, 2005), 3.

the more negative and coercive strategies of the eugenics movement. The second new package, *public health genetics*, the application of human genetic science to benefit the hereditary health of an entire population, was created organizationally in 1959. Although respectful of individual choice, public health genetics entailed more coercive elements than did genetic counseling in assuming that human genetics was a concern of the state and that individuals had a responsibility to cooperate with genetic screening procedures and follow recommended interventions and treatments. In that way, public health genetics was more similar to eugenics than genetic counseling.

Human geneticist James V. Neel (1915–2000) made the distinction between *genetic counseling*, which he defined as "an effort to bring the patient or some responsible individual to an understanding of a problem without at the same time attempting to impose a decision involving a course of action on that patient or individual" and *eugenics*, "an attempt to influence the reproductive behavior of an individual or group in either a positive or negative fashion, through legislation or persuasion." Neel told a national gathering of pediatricians in 1956 that, "we have a sufficient knowledge of human genetics to provide in a variety of situations information of real value to patients," but "we do not as yet have the overall knowledge of human genetics which is basic to an intelligent eugenic program." He continued to express misgivings about applying genetic science to groups of people throughout his long and distinguished career. <sup>15</sup>

<sup>&</sup>lt;sup>13</sup> James V. Neel and William J. Shull, *Human Heredity* (Chicago: University of Chicago Press, 1954).

<sup>&</sup>lt;sup>14</sup> James V. Neel, notes of talk to American Academy of Pediatrics, October 9, 1956, Series VI, box 1, folder "1956–1959," Papers of James V. Neel, American Philosophical Society.

<sup>&</sup>lt;sup>15</sup> James V. Neel, *Physician to the Gene Pool: Genetic Lessons and Other Stories* (New York, NY: J. Wiley & Sons, 1994).

# **Eugenics and Public Health**

Similarities in values and goals between proponents of the eugenics movement and leaders of the simultaneously developing field of public health went practically unmentioned in the early twentieth century. Instead, the two endeavors were portrayed as being at odds with one another because of the assumption that public health programs delayed the demise of the unfit and allowed some of them to live long enough to reproduce and pass their defects to their children. Another difference between the two fields was that proponents of eugenics focused their strategies on relatively small numbers of individuals who exhibited characteristics they considered to be unfortunate and hereditary, while the public health field concentrated on improving the health of entire populations.

Public health practitioners in the early part of the twentieth century worked mainly on the prevention and control of infectious diseases and only later, in the 1920s, focused on topics of interest to eugenicists such as maternal and child health, chronic diseases, mental deficiency, and genetic impairments. Some eugenicists questioned the basic public health belief that infectious agents caused disease, preferring to think that constitutional susceptibility to such diseases was more important. Nonetheless, Stern's study of the early twentieth century eugenics movement in California concluded that eugenics and public health shared philosophical beliefs rather than being ideologically opposed. Both movements derived underlying values from the Progressive Movement, such as belief in heredity as destiny, faith that human life could be improved through the

<sup>&</sup>lt;sup>16</sup> Pernick, "Eugenics and Public Health."

<sup>&</sup>lt;sup>17</sup> Pernick, "Eugenics and Public Health."

enlightened application of science, and belief that government was obligated to safeguard the well being of people. 18 Progressive ideals thus pervaded both eugenics and public health in the early twentieth century.

After World War II, people had good reason to be interested in the population aspects of genetics. They were concerned about radiation damage to human genes from atomic bombs and nuclear weapons testing. In addition to radiation fears, people were alarmed about possible genetic damage from environmental pollution and the exponential increase in global human population that they thought might adversely affect the quality of the gene pool. People in the post-war era were also more aware of genetics than in the past because of the discovery of new genetic diseases (and their treatments) and new technology and options to manage their reproductive choices. Genetics and previously taboo topics such as birth control commonly entered into private and public discussions.

Victims of hereditary impairments such as Huntington's disease and phenylketonuria (PKU) sometimes required institutionalization and created a burden on the extensive system of state-run custodial hospitals that existed after World War II. As genetic diseases came to be better understood, administrators in public institutions for the insane, criminal, and feebleminded recognized that some of the inmates suffered from genetic conditions previously not understood as hereditary. By preventing births of genetically disabled individuals, public health genetics offered strategies to reduce the high financial cost to society of institutional lifetime care for the hereditarily impaired.

<sup>18</sup> Stern, Eugenic Nation."

#### **Public Health Genetics**

Public health genetics programs such as disease screening, disease registries, and genetic counseling for entire populations, were activities without direct precedents. They expanded rapidly after being established in 1960 in Minnesota. Within five years, nearly every state in the United States had a genetic component to its health department, and genetic disease came to be approached similarly to other public health issues. With new knowledge about genetics and tools for intervening on a population level, public health officials had high hopes for drastically reducing the burden of genetic disease in the population and controlling the financial cost to society. The field of public health genetics can be interpreted as the heir of eugenics insofar that it endeavored to apply genetic science to populations to improve the quality of the gene pool and reduce the financial burden of genetic disease.

The practice of public health genetics not only grew out of previous formulations of human genetics, including eugenics, but it was also shaped by the development of the public health system itself. Public health practitioners and leaders had to be ready to accept the relevance of genetics to their field and that meant that they first had to incorporate the chronic metabolic diseases as public health responsibilities and develop the techniques to study such diseases. At the same time, broad societal understanding of genetic science and its principles were required to gain public support for collective action about genetics and to frame it as a legitimate public concern. <sup>19</sup> In 1959 these two pre-requisites came together in Minnesota, and the legislature accepted the premise that

<sup>&</sup>lt;sup>19</sup> Charles E. Rosenberg, "Framing Disease: Illness, Society, and History," in *Framing Disease: Studies in Cultural History*, eds. Charles E. Rosenberg and Janet Golden (New Brunswick, NJ: Rutgers University Press, 1997), xiii-xv.

human genetics constituted an important consideration for the common good and a responsibility of the state.

Almost as suddenly as the program in public health genetics had appeared in 1959, cultural shifts and advances in medical technology combined in the early 1970s to cause a rapid decline in public health genetics practice. Experience with programs in state health departments revealed that genetics and public health were not a particularly good fit because public health applications of genetic science were limited. Some of the functions of human genetics units in state health departments migrated to the personal medical care system, and the units gradually shrank in size and responsibility. Social and political support for public health genetics also eroded with the cultural revolution of the 1960s and 1970s that elevated individual rights over the greater good. In the 1980s, some public health genetic activities such as disease registries and mandatory genetic screening of newborns began to encounter opposition from groups concerned about individual privacy rights. These libertarian and anti-government groups believed strongly that public health genetic programs violated their right to privacy and freedom from governmental intrusion.

# Four Families with Genetic Afflictions: Why Genetics is Both Private and Public

The following stories of four Upper Midwestern American families affected by a pair of genetic diseases are presented as a backdrop to the dawn of public health genetics.

These stories—about hemolytic disease of the newborn (Rh factor incompatibility)<sup>20</sup> and

<sup>&</sup>lt;sup>20</sup> Cowan, Heredity and Hope, 74-78

Huntington's disease<sup>21</sup>—are not intended to review the clinical features of the two conditions or to discuss their severity, treatment, or preventability. These family stories instead illustrate that genetic diseases were personal tragedies about which wrenching private decisions had to be made. They show the suffering the diseases caused for the families, the lost productivity, and the financial burden on the state for institutional care. The two conditions, erythroblastosis fetalis and Huntington's disease, illustrate why some genetic abnormalities are not just private, but also become public concerns. Huntington's disease in particular had a public dimension because many of its sufferers required lifelong custodial care in state institutions. The disease seemed to many people to require special strategies available only to state health departments, services such as a population-based disease registry and universal access to genetic counseling for those families at risk for the disease.

# Family 1. Erythroblastosis Fetalis

Mavis Geneva Holtan (1916–1988), my aunt, was the oldest of five in her Norwegian–American family. She was beautiful, had a sweet personality, and could sing like an angel. After completing high school, she married Iowa farmer Lloyd Lovik and settled near the auspiciously named village of Fertile, Iowa, to start a big family. That might have happened except for the Holtan genetic tendency to have red blood cells that

<sup>&</sup>lt;sup>21</sup> Alice Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease* (New Haven, CT: Yale University Press, 2008).

<sup>&</sup>lt;sup>22</sup> George T. Holtan, Agnes Brackey, and Carl C. Holtan, *Holtan Family History* (Lake Mills, IA: Graphic Publishing Company, 1950).

are Rhesus (Rh) factor negative.<sup>23</sup> Rh negative mothers exposed during the birth process to the blood of Rh positive babies can manufacture antibodies to Rh positive blood cells that cause complications for subsequent Rh positive babies. If the next fetus is Rh positive, maternal antibodies cross the placenta and attack the fetus's blood cells to cause a condition called eythroblastosis fetalis that ranges in severity from mild anemia to fetal death. Severely affected babies who survive suffer deafness, retardation, and spastic quadriplegia.<sup>24</sup>



Figure 1. Mavis Geneva (Holtan) Lovik, on the occasion of her confirmation in the Lutheran Church, May 11, 1930. (Collection of author)

 $<sup>^{23}</sup>$  Rh negative status is common in people of northern European background (a prevalence of about 15 percent compared with 5 percent for Africans and almost zero in Asians).

<sup>&</sup>lt;sup>24</sup> Howard A. Pearson, "Hemolytic Diseases of the Newborn Due to Rh Incompatibility," in *Textbook of Pediatrics*, eds. Waldo E. Nelson, Victor C. Vaughn, R. James MaKay (Philadelphia, PA: W.B. Saunders Company, 1969), 1060–63.

My cousin Marcus was born in 1939. He probably sensitized his mother to Rh positive red blood cells and caused her to manufacture antibodies to them. The second child, Linda Marie, born in 1940, was severely anemic at birth. She lived for only two months and was buried in the country churchyard. Lamar arrived healthy in 1942, probably Rh negative like his mother. The fourth baby a year later was stillborn and did not receive a name or a tombstone. Mavis knew that the fifth baby was dead a month before it was born. Her antibodies had crossed the placentas of the babies and killed them.

Mavis's extended family did not understand the reason for the babies' deaths and did not talk about the subject. We eventually learned that the cause of the newborn and fetal deaths had been Rh incompatibility after the condition became known in the 1950s. <sup>26</sup> Likewise, we did not talk about Mavis's obvious and lifelong sadness. She made the best of her life of hard work on the farm and stopped singing except on Christmas Eve when her glorious voice soared above all of ours.

# Family 2. Erythroblastosis Fetalis

One hundred miles north of Fertile, in Minneapolis, Minnesota, about a decade later, another husband and wife experienced the same problem with Rh as had the Loviks. The Reeds lived at a time when physicians knew more about Rh factor incompatibility and how to treat and prevent it. Sheldon Clark Reed and his wife, Elizabeth Warren Reed, were both Ph.D.-trained geneticists. In 1947, Sheldon Reed became the second director of

<sup>&</sup>lt;sup>25</sup> Personal communication, Wendy Holtan Pothast as remembered from Arlene L. (Bolstad) Holtan, April 12, 2009.

<sup>&</sup>lt;sup>26</sup> Personal communication, Boyd D. Holtan, Mavis Lovik's brother, April 13, 2009.

the Dight Institute for Human Genetics at the University of Minnesota. During the couple's second pregnancy in 1948, blood tests showed that Elizabeth had antibodies to Rh factor. They decided to forgo additional children and spare themselves the agony of subsequent stillborn or physically damaged babies. Elizabeth had tubal ligations during her Cesarean section. Sheldon confided this information to his colleague and friend, James V. Neel, saying, "It seems to me that most people who will voluntarily 'compensate' would go the whole way and not risk any more children." <sup>27</sup>

### Family 3. Huntington's Disease

A woman we will call Hilda entered Iowa's Clarinda State Mental Hospital in 1948 with Huntington's disease. Born in Germany in 1889, she came to Iowa at the age of 4. Hilda had an unhappy childhood because of her mother's mysterious nervous condition. At age 17, Hilda married an Iowa farmer and they had ten children. In the late 1920s Hilda's family noticed progressively bizarre behavior. In 1933, she started to experience involuntary jerking and shaking movements. Her husband began to push her around, make fun of her, withhold food, and lock her up in rooms in the house. Her children committed their father to Clarinda in 1937 where he died in 1945 from depression, agitated senile psychosis, and alcoholism.

Even without her husband's abuse, Hilda became more and more mentally ill with unreasonable fear of storms, constant loud talking, erratic behavior, and refusal to bathe. Her involuntary jerking movements became so severe that her children could no longer care for her and in 1947 they committed her to Clarinda where she was diagnosed with

<sup>&</sup>lt;sup>27</sup> Sheldon Reed to James Neel, November 12, 1951, series I, folder "Correspondence R-Ri," James V. Neel Papers, American Philosophical Society.

Huntington's disease. The psychiatrist identified twenty of Hilda's relatives with Huntington's, including nine past and present inmates of Clarinda.

The psychiatrist was surprised to find different degrees of denial and secrecy among the children. One daughter, a registered nurse, wrote,

I have always been ashamed of my mother for her odd behavior and jerking movements. Even as a small girl I wondered why she was different from mothers of my friends. She was always so loud when talking, was very nervous and a source of worry and embarrassment to me. In later years I worried considerably about her condition and wondered if it was hereditary. It seems there is too much of this in our family for it to be otherwise.

According to the psychiatrist, Hilda's oldest son was extremely difficult to interview because of "his reticence, evasiveness, and denial of his mother's actual symptoms, although from other sources we know he was familiar with her behavior and family background."<sup>28</sup>

The psychiatrist concluded that "the terrific price these families pay in emotional instability, fear, and anxiety, notwithstanding should be remembered in addition to the huge cost of hospital maintenance which the taxpayers of Iowa have paid and will pay for this family." He recommended that the State of Iowa ought to counsel Hilda's children and offer to pay for voluntary surgical sterilization for those who agreed.

# Family 4. Huntington's Disease

Sarah (Sally) Ann Corl married Herbert Richard Hogan in Minneapolis in 1950. They had two children, Richard (Rick) Paul, born in 1951, and Janet (Jan) Susan, born in 1953. Herb became unexpectedly aggravated by Jan's crying and to Sally's horror, struck

<sup>&</sup>lt;sup>28</sup> Victor Zike and Norman D. Render, "Huntington's Chorea," *The Journal of the Iowa State Medical Society* 39 (August 1949): 386–88.

the baby, the first sign of a change in his usually gentle personality. Over a period of years, he abused his wife and children physically and emotionally. Sally unsuccessfully tried counseling to understand what was happening, and in 1960 she asked Herb to leave their house to live with his mother. Soon afterwards he began to have involuntary jerking movements. By 1965 he could no longer work as a freight handler with the Great Northern Railway in Minneapolis. In 1966, Sally took him to the Minneapolis Veterans' Administration Hospital where neurologists diagnosed Huntington's disease. In 1967 Herb required admission to a nursing home and then to the St. Cloud Veterans Administration Hospital where he died from choking in September 1974.

After learning Herb's diagnosis in 1966, Sally made an appointment with Sheldon Reed at the University of Minnesota. Reed expressed surprise that he had not seen the Hogan name among Huntington's disease families in Minnesota. Sally told him that Herb had come from an orphanage in New York. Reed provided Sally with genetic counseling about Huntington's disease and Sally learned that her children each had a 50/50 chance of developing it. Sally began to search for more information about Herb's family background. Even though his adoptive family in Minneapolis was not helpful, Sally found out that at the age of 3, Herb had come from a hospital and orphanage in Rome, NY, to be raised by the Hogans. His adoptive mother's sister, a physician at the Rome facility, had arranged it. Although the Hogans and Herb's aunt knew about his birth mother's Huntington's disease, no one had told Sally.

The Hogan family was particularly unlucky. Daughter Jan began to have symptoms of Huntington's disease at the unusually young age of 9. Manifestations began with a hand tremor, and Jan subsequently developed other severe neurological symptoms.

She finished high school with great difficulty because the tremors made it difficult to write or walk. Even though her father was known to have Huntington's disease, physicians did not diagnose Jan's early onset Huntington's disease until 1972 when she was 19. Three years later she expired in a nursing home.

Son Rick joined the Marine Corps the day he graduated from high school in 1967. His four years as a marine included several courts martial and nine months in a military psychiatric unit with a diagnosis of schizophrenia. In 1973 when he returned to Minnesota, he was distressed about Jan's illness, but in 1974 he got married and started college. Within a year his wife divorced him and committed him to the Minneapolis Veterans Administration Hospital as insane. In 1975 he was diagnosed with Huntington's disease and admitted to the St. Cloud Veterans' Administration Hospital where his father had died nine years earlier. Rick ran away from St. Cloud many times, eventually going to Hawaii in 1978 and later to California where he ended up in another veterans' hospital for the rest of his life. He refused to allow visits from his mother and died at age 38.

Sally found that few people had the strength to support her as she watched her family sicken and die one after the other. She experienced the lack of social resources for Huntington's families. For fifteen years starting in 1970, she volunteered with the Minnesota chapter of the Committee to Combat Huntington's Disease, the national organization that had been started by Marjorie Guthrie in 1967. From 1979 to 1985 she worked at the Dight Institute at the University of Minnesota under a federal grant to support Huntington's families. In 1985, to preserve her mental health, she stopped volunteering and working with Huntington's families and changed careers, becoming the

secretary to medical chiefs of staff at two different Minneapolis hospitals. She retired in 1991 and lives in Eden Prairie, Minnesota.<sup>29</sup>

# **Assigning Meaning Through History**

Environmental historian William Cronin has analyzed interpretations of the 1930s Dust Bowl in the Great Plains of the United States to understand how different historians framed climatic events in starkly different favorable and unfavorable ways. He concluded his paper with a series of questions to stimulate thought about how the historians assign meaning to what happened. I loosely paraphrase his questions here, changing Dust Bowl to genetics, to discover meaning in the history of public health genetics. First, why do people care about their genes and go about assigning meaning to their heredity? Second, how do people's understanding of their genes and their desires for a healthy population shape the study and application of human genetics? Third, what sort of heredity do people want for others and how do they struggle with each other for control of human genes and their meaning?

The answers to these questions about public health genetics are neither singular nor consistent over time and place. This study investigates how one community, the State of Minnesota, worked to find answers that could be used for public policy and how the practice of public health genetics fell within its cultural traditions and state institutions.

<sup>&</sup>lt;sup>29</sup> Sarah (Sally) Corl Hogan interview by Neal Ross Holtan, January 11, 2008, available from the author in digital audio or transcription formats; transcript available, digital audio format pending, Oral History Collection, University of Minnesota Archives.

<sup>&</sup>lt;sup>30</sup> William Cronon, "A Place for Stories: Nature, History and Narrative," *Journal of American History* 78 (March, 1992): 1347–76.

#### **CHAPTER 2**

# Charles Dight and the Minnesota Eugenics Society, 1926–1938

Nobody pleads the sacred rights of the individual when contagious diseases spread, . . . Why, then, should we be so tender about the prerogatives of those who are mentally unfit to manage themselves, who are an ever increasing burden on the public, who cause both loss of life and loss of property, and who are the principal cause of all human misery and suffering?

— G.C. Hanna, Superintendent of Minnesota's School for the Feeble-minded, 1925.

The eugenics movement in the early twentieth century provides the starting point for the story of human genetics in Minnesota and its eventual manifestation as public health genetics. The eugenic movement's two most important outcomes in Minnesota consisted of its campaign for passage of the 1925 surgical sterilization law for inmates at the School for the Feeble-Minded in Faribault and its role in establishing the Dight Institute for Human Genetics at the University of Minnesota in 1941.

Eugenics, like public health genetics decades later, was an attempt to apply genetic science, as it was known, to improve the quality of human populations.<sup>32</sup> In recent decades, the word *eugenics* has accumulated powerful negative connotations and

<sup>&</sup>lt;sup>31</sup> G.C. Hanna, "The Menace of the Feebleminded," in *Proceedings of the Quarterly Conference of the Minnesota Board of Control* 4, no. 3 (1925): 21–53.

<sup>&</sup>lt;sup>32</sup> Mark Haller, *Eugenics: Hereditarian Attitudes in American Thought* (New Brunswick, NJ: Rutgers University Press, 1963); Daniel J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (New York, NY: Alfred A. Knopf, 1985), second edition with new preface by the author (Cambridge, MA: Harvard University Press, 1995). For a cultural history of eugenics, see Wendy Kline, *Building a Better Race: Gender, Sexuality, and Eugenics from the Turn of the Century to the Baby Boom* (Berkeley, CA: University of California Press, 2001). For intellectual, political, and social history of eugenics, see the essays of Diane B. Paul, *The Politics of Heredity: Essays on Eugenics, Biomedicine, and the Nature–Nurture Debate* (Albany, NY: The State University of New York Press, 1998) and *The Politics of Heredity: Essays on Eugenics, Biomedicine, and the Nature–Nurture Debate* (Albany, NY: The State University of New York Press, 1998).

emotional weight.<sup>33</sup> Minnesota's experience with eugenics in the early twentieth century thus offers an opportunity to step back to the time when eugenics was not as feared and abhorred as it later has become and to reflect on what the movement intended, particularly in regard to its greater goal of improving the hereditary health of populations.<sup>34</sup>

Many historians have focused on broad social and political themes to understand the eugenics movement.<sup>35</sup> They have not, however, paid as much attention to the public health implications of eugenics.<sup>36</sup> An exception is Alexandra Stern, who explored associations among eugenics, United States colonialism at the turn of the twentieth century, stigmatization of aliens (Chinese, Mexicans) as disease carriers, and belief in science to control both infectious diseases and so-called "race degeneracy." Stern's analysis of eugenics in the American West does not necessarily apply directly to Minnesota's experience, but parallels existed in Minnesota between eugenic concern about uncontrolled spread of hereditary disease and fear of contagion by microorganisms. Leaders of the eugenics movement in Minnesota consistently used public health concepts

<sup>&</sup>lt;sup>33</sup> For an overview of the history of eugenics, see Ruth Schwartz Cowan, "Eugenics and the Genealogical Fallacy," in *Heredity and Hope: The Case for Genetic Screening* (Boston, MA: Harvard University Press, 2008), 41-70.

<sup>&</sup>lt;sup>34</sup> Kenneth M. Ludmerer, "American Geneticists and the Eugenics Movement: 1905–1935," *Journal of the History of Biology* 2 (1969): 337–62.

<sup>&</sup>lt;sup>35</sup> Diane B. Paul, "What is Eugenics? Why Does It Matter?" in *Controlling Human Heredity:* 1865 to the Present (Amherst NY: Humanity Books, 1998), 1–22. For negative analyses of eugenics, see Edwin Black, War Against the Weak: Eugenics and America's Campaign to Create a Master Race (New York, NY: Four Walls Eight Windows, 2003) and Steven Sheldon, Inheriting Shame: The Story of Eugenics in America (New York, NY: Teachers College Press, 1999).

<sup>&</sup>lt;sup>36</sup> Martin S. Pernick, "Eugenics and Public Health in American History," *American Journal of Public Health* 87 (1997): 1767–72.

<sup>&</sup>lt;sup>37</sup> Alexandra Minna Stern, *Eugenic Nation: Faults and Frontiers of Better Breeding in Modern America* (Berkeley, CA: University of California Press, 2007).

and goals such as the control of communicable diseases as a metaphor for eugenics. Analysis along those lines is difficult because the field of public health itself was evolving over the same decades as eugenics and human genetics. We, like Stern, however, can look for public health thinking within the contours of the eugenics movement.

The founder of the eugenics movement was Great Britain's Francis Galton (1822–1911), Charles Darwin's cousin, who proposed in the 1860s to apply selective breeding to humans. <sup>38</sup> He coined the term *eugenics* in 1883. Galton's interest in eugenics stemmed from his study showing that eminent Englishmen commonly were blood relatives of other famous individuals. <sup>39</sup> He concluded that superior humans could be produced the same way that breeders produce better strains of animals by encouraging the union of mates with the best hereditary characteristics. <sup>40</sup> Galton favored positive eugenics, encouraging the "right" people to marry, based on their levels of occupational and social success, and asking them to have more offspring. That goal proved difficult. During the decades that followed, proponents of negative eugenics, that is, discouraging the "wrong" people from reproducing through placing limitations on their ability to reproduce, found broader, more practical applications than those favoring positive eugenics. <sup>41</sup>

<sup>&</sup>lt;sup>38</sup> Daniel J. Kevles, "Francis Galton: Founder of the Faith," in *In the Name of Eugenics*, 1985.

<sup>&</sup>lt;sup>39</sup> Francis Galton, *Hereditary Genius: An Inquiry into Its Laws and Consequences* (London, UK: MacMillan, 1869).

<sup>&</sup>lt;sup>40</sup> Ruth Schwartz Cowan, *Sir Francis Galton and the Study of Heredity in the Nineteenth Century* (Ph.D, dissertation, The Johns Hopkins University, 1969), published in the series, "The History of Hereditarian Thought," ed. Charles Rosenberg (New York, NY: Garland Publishing, 1985); Nicholas W. Gillham, "Sir Francis Galton and the Birth of Eugenics," *American Review of Genetics* 35 (2001): 83–101.

<sup>&</sup>lt;sup>41</sup> Kevles, In the Name of Eugenics, 4–5.

People in the late nineteenth and early twentieth centuries believed that most human characteristics and behaviors, including intelligence, were hereditary. During Galton's time, no one made much distinction between inborn and acquired characteristics, and all were thought to be hereditary. After the 1900 rediscovery of Gregor Mendel's (1822–1884) 1867 research on the pattern of inherited characteristics in garden peas and the discovery in 1915 that genes and chromosomes were the mechanisms for conveying inheritance from parent to offspring, very few people disputed the conclusion that genetic characteristics were inborn. The alternative, Lamarckian inheritance, the theory that acquired human characteristics can be passed to offspring, succumbed to Mendelian genetics. As one Minnesota physician put it, "You can inherit a wooden head but not a wooden leg."

In the first third of the twentieth century, 32 states passed laws allowing surgical sterilization for eugenic reasons, the first being Indiana in 1905 and the twenty-fifth Minnesota in 1925.<sup>47</sup> Harry C. Sharp, the surgeon at Indiana's men's reformatory, spoke

<sup>&</sup>lt;sup>42</sup> Carl N. Degler, *In Search of Human Nature: The Decline and Revival of Darwinism in American Social Thought* (New York, NY: Oxford University Press, 1991), 42.

<sup>&</sup>lt;sup>43</sup> Charles E. Rosenberg, "The Bitter Fruit: Heredity, Disease, and Social Thought," in *No Other Gods: On Science and American Social Thought* (Baltimore: Johns Hopkins University Press), 25–53.

 $<sup>^{44}</sup>$  Curt Stern, "Mendel and Human Genetics," *Proceedings of the American Philosophical Society* 109, no. 4 (August 1965): 216–26.

<sup>&</sup>lt;sup>45</sup> Diane B. Paul, "From Soft to Hard Heredity," in Controlling Human Heredity, 40–9.

<sup>&</sup>lt;sup>46</sup> W. A. Jones, "Care and Treatment of the Psychoneurotic," *Minnesota Medicine* 8 (1925): 578.

<sup>47</sup> Mark A. Largent, *Breeding Contempt: The History of Coerced Sterilization in the United States* (New Brunswick, NJ: Rutgers University Press, 2007); Philip R. Reilly, *The Surgical Solution: A History of Involuntary Sterilization in the United States* (Baltimore: The Johns Hopkins University Press, 1991). For accounts of eugenics movements in states or regions, see Nancy L. Gallagher, *Breeding Better Vermonters: The Eugenics Project in the Green Mountain State* (Hanover, NH: University Press of New England, 1999); Edward J. Larson, *Sex, Race, and Science: Eugenics in the Deep South* (Baltimore: Johns Hopkins University Press, 1995); and Stern, *Eugenic Nation*.

in 1908 to the Minnesota State Board of Control, the group of appointees who managed Minnesota's state institutions, about Indiana's law for the sterilization of criminals, idiots, imbeciles, and rapists. Such individuals, according to Sharp, suffered from "degeneracy," a condition that was incurable and hereditary, "something lacking in the mental or nervous construction." Degenerates, defined by Sharp as "the insane, the epileptic, the imbecile, the idiotic, the sexual perverts; many of the confirmed inebriates, prostitutes, tramps and criminals; as well as the habitual paupers found in our county poor asylums" were costly to society economically. Sharp recommended vasectomy, a "simple and harmless operation" that benefited the institutionalized teenage boy because he "has a better disposition, and is brighter of intellect, ceases excessive masturbation, and advises his fellows to submit to the operation for their own good."

Intelligence testing, like genetics, was a new development that affected the theory and practice of eugenics in the early twentieth century.<sup>51</sup> At the 1909 annual meeting of the American Association for the Study of the Feeble-Minded, neurologists and psychiatrists enthusiastically endorsed psychologist Henry Goddard's (1866–1957) first report of the use of intelligence testing at the New Jersey Training School for Feeble-Minded Boys and Girls in Vineland.<sup>52</sup> Intelligence testing rapidly spread to schools,

<sup>&</sup>lt;sup>48</sup> Harry C. Sharp, "The Sterilization of Degenerates," in *Proceedings of the Quarterly Conference of the Minnesota Board of Control* 7 no. 3 (1908): 79–94. For a discussion of Sharp's role in the promotion of vasectomy as a eugenic measure, see Largent, *Breeding Contempt*, 28–31.

<sup>&</sup>lt;sup>49</sup> Sharp, "The Sterilization of Degenerates."

<sup>50</sup> Sharp, "The Sterilization of Degenerates."

<sup>&</sup>lt;sup>51</sup> Michael M. Sokal, "Introduction: Psychological Testing and Historical Scholarship–Questions, Contrasts, and Context," in *Psychological Testing and American Society, 1890–1930*, ed. Michael M. Sokal (New Brunswick: Rutgers University Press, 1987), 1–20.

<sup>&</sup>lt;sup>52</sup> Leila Zenderland, Measuring Minds: Henry Herbert Goddard and the Origins of American Intelligence Testing (New York, NY: Cambridge University Press, 1998).

institutions, and prisons in the United States.<sup>53</sup> In 1917 United States Army psychologists applied IQ tests to more than a million and a half military recruits for World War I and reported to a shocked nation that a significant number of the healthy young men had tested as feeble-minded. <sup>54</sup> The army psychologists claimed that the intelligence tests showed intelligence to be inherited. <sup>55</sup> They did not recognize class bias inherent in the test questions or errors in interpreting the results of the tests, shortcomings soon noticed by other psychologists. <sup>56</sup> By 1930, researchers concluded that ninety percent of what had been measured on the army "intelligence" tests consisted of achievement rather than innate mental capacity. <sup>57</sup> Justified or not, physicians and the educated public in the 1920s were left with the impression that intelligence testing was scientifically sound.

In 1919, Arthur Sweeney, a Saint Paul psychiatrist, described his experience with intelligence testing as head of the psychiatric division at Iowa's Camp Dodge during World War I. He called the results "surprising and bewildering . . . somewhat of a shock to realize that the average of human intelligence in this country is that of a child of about 12 years of age." Sweeney believed that intelligence was inherited and not dependent on education or social status, but he did not favor sterilization, for practical reasons. "Who is

<sup>&</sup>lt;sup>53</sup> Leila Zenderland, "The Debate over Diagnosis: Henry Herbert Goddard and the Medical Acceptance of Intelligence Testing," in *Psychological Testing and American Society*, *1890–1930*, ed. Michael Sokal (New Brunswick, NJ: Rutgers University Press, 1987), 46–74.

<sup>&</sup>lt;sup>54</sup> Daniel J. Kevles, "Testing the Army's Intelligence: Psychologists and the Military in World War I," *The Journal of American History* 55 (1968): 565–81; James Reed, "Robert M. Yerkes and the Mental Testing Movement," in *Psychological Testing and American Society*, ed. Michael Sokal (New Brunswick, NJ: Rutgers University Press, 1987), 75–94.

<sup>&</sup>lt;sup>55</sup> Robert M. Yerkes, "What Psychology Contributed to the War," in *The New World of Science: Its Development During the War*, The Century New World Series, ed. Robert M. Yerkes (New York, NY: New Century Co., 1920), 351–89.

 $<sup>^{56}</sup>$  M. R. Neifeld, "The Race Hypothesis," *The American Journal of Sociology* 32 (1926): 423–32.

<sup>&</sup>lt;sup>57</sup> Paul A. Witty and Harvey C. Lehman, "The Dogma and Biology of Human Inheritance," *American Journal of Sociology* 35 (1930): 548–63.

to determine the ones upon whom vasectomy is to be imposed, and who is wise enough to convince people that they should not marry? Will people tolerate and enforce laws that limit what is regarded as natural function?"<sup>58</sup> In spite of these misgivings about mandatory sterilization, Sweeney agreed in 1926 to serve on the advisory council of the Minnesota Eugenics Society, the organization that had actively promoted the 1925 eugenic sterilization law.<sup>59</sup>

### Minnesota's Program to Care for the Feeble-Minded

The Minnesota Legislature created the State Board of Control in 1901 to manage the state's institutions other than the university.<sup>60</sup> The Board had responsibility for sixteen facilities including prisons, reformatories, insane asylums, tuberculosis hospitals, and reform schools.<sup>61</sup> It also administered the involuntary commitment laws passed in 1907 for the insane and in 1917 for the mentally defective.<sup>62</sup> Panels of experts made up of a county probate judge and two physicians appointed by the judge determined whether the person was mentally defective and if he or she needed state guardianship. No particular expertise in assessing the mental capacity of an individual was required. The panel took into consideration the social situation of the person, adequacy of home

<sup>&</sup>lt;sup>58</sup> Arthur Sweeney, "The Measure of Mentality," *Minnesota Medicine* 3 (1920): 1–15.

 $<sup>^{59}</sup>$  Arthur Sweeney to George G. Eitel, April 5, 1926, box 5, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>60</sup> "History of the State Board of Control, 1901–1922," 1922, box 2, State Board of Control Records, Minnesota Historical Society.

<sup>&</sup>lt;sup>61</sup> For an overview of the history of what was called "feeble-mindedness," James W. Trent, Jr., "The Menace of the Feebleminded," in *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (Berkeley, CA: University of California Press, 1994), 131–83.

<sup>&</sup>lt;sup>62</sup> Frederick Kuhlmann, pamphlet, "Determination of Feeble-Mindedness as Related to the Courts," from an address to the State Association of Probate Judges (State Board of Control, January 15, 1920), box 2, State Board of Control Records, Minnesota Historical Society, 1-19.

support, and ability to manage his or her affairs. At the end of the assessment, the panel decided for or against commitment to the care of the State Board of Control. The Board had the options of placing the person in a private home, a boarding home, or the state's institution for the feeble-minded, the School for the Feeble-Minded at Faribault.<sup>63</sup> Only a small proportion of Minnesota's feeble-minded residents lived at the school after commitment.

In addition to segregating the feeble-minded at the facility in Faribault, Minnesota used the negative eugenic strategy of restricting marriage patterned after Connecticut's 1896 law. In 1901, the Minnesota Legislature forbade the marriage of any woman under the age of 45 or a man of any age likely to father children, if either partner were "epileptic, imbecilic, feeble-minded, or afflicted with insanity." The State Board of Control had the power to investigate marriage requests that might violate the law and establish guardianship over vulnerable individuals if necessary. The problem with marriage restriction laws, as H. C. Sharp noted, was that "unfortunately matrimony is not always necessary to propagation." 64

Minnesota's School for the Feeble-Minded was located on a wooded bluff above the Straight River in Faribault, a city fifty miles south of Minneapolis. <sup>65</sup> Originally founded in 1882 as the School for Idiots and Imbeciles, the name had been changed to the School for the Feeble-Minded and Colony for Epileptics in 1887. The institution

<sup>&</sup>lt;sup>63</sup> Frederick Kuhlmann, "The State's Program for the Feeble-Minded," in *Proceedings of the Quarterly Conference of the Minnesota Board of Control* 27, No. 1 (September 16, 1927): 48–64.

<sup>&</sup>lt;sup>64</sup> Sharp, "The Sterilization of Degenerates."

<sup>&</sup>lt;sup>65</sup> J. M. Murdoch, "The Institution—The Minnesota School for the Feeble-Minded," in *Proceedings of the Quarterly Conference of the Minnesota Board of Control* 27, No. 4 (May 15, 1928): 5–12.

provided training and custodial care for the feeble-minded, controlled the behavior of the inmates, and protected them from exploitation. In its early years the School operated under the assumption that, given training, the inmates could become self-sufficient, productive members of society and live independently outside the school. As experience grew, people realized that developmental progress among the young inmates leveled off and possibly declined in adulthood, giving way to thinking that the best to be expected was that feeble-minded adults could live in self-sustaining institutions. With the Great Depression, sterilization gained impetus as the means to address institutional overcrowding and high costs of caring for the feeble-minded by allowing them to return safely to their communities.

The school at Faribault eventually grew large. In 1928, it had 1,145 acres of land—576 under cultivation—and a population of about 2,000 inmates, 300 employees, 100 Holstein cows, 26 teachers, 3 physicians, and 2 visiting surgeons. The staff, with support from the State Board of Control, conducted research into feeble-mindedness and its causes and reported their findings in professional journals and at national meetings.

<sup>&</sup>lt;sup>66</sup> Walter E. Fernald, "The History of the Treatment of the Feeble-Minded," in *Proceedings of the National Conference of Charities and Corrections* (1893): 203–21.

<sup>&</sup>lt;sup>67</sup> Peter Tylor, "Denied the Power to Choose the Good: Sexuality and Mental Defect in American Medical Practice 1850 to 1920" *Journal of Social History* 10 (1977): 472–89.

<sup>&</sup>lt;sup>68</sup> James W. Trent, "To Cut and Control: Institutional Preservation and the Sterilization of Mentally Retarded People in the United States, 1892–1947," *Journal of Historical Sociology* 6 (1993): 56–73.

<sup>&</sup>lt;sup>69</sup> Murdoch, "The Institution—Minnesota School for the Feeble-Minded."

<sup>&</sup>lt;sup>70</sup> Kuhlmann, "The State's Program."

#### **Discussion about Genetics and Eugenics**

Eugenics had long been a topic considered by the State Board of Control. David Star Jordan (1851–1931), biologist, president of Stanford University, and one of the most influential promoters of eugenics in the United States, addressed their quarterly meeting in the Senate Chamber at the Minnesota Capitol in August 1912. He told them that, "The purpose of the study of eugenics is to know the kind of ancestors we should pick for the next generation." Three months later, the State Board of Control heard a lecture by another nationally prominent supporter of eugenics, Harvard biologist Charles Benedict Davenport (1866–1944). Davenport asserted that human characteristics such as alcoholism, feeble-mindedness, criminal behavior, prostitution, sexual promiscuity, and a propensity to "wander" were hereditary. He focused on the heredity of feeble-mindedness caused by the lack of the "determiner" for proper mental development. As proof, Davenport referred to research on families with feeble-mindedness running through the generations of several unfortunate clans. In contrast, he cited New England's Edwards family with its generations of geniuses, scholars, and public

<sup>&</sup>lt;sup>71</sup> David Starr Jordan, untitled address, in *Proceedings of the Quarterly Conference of the Minnesota State Board of Control* 12, no. 1 (August 1912): 3–19.

 $<sup>^{72}</sup>$  Kevles, "Charles Davenport and the Worship of Great Concepts," in *In the Name of Eugenics*, 41–56.

<sup>&</sup>lt;sup>73</sup> Charles E. Rosenberg, "Charles Benedict Davenport and the Irony of American Eugenics," in *No Other Gods: On Science and American Social Thought* (Baltimore: Johns Hopkins University Press, 1976), 89–97. Davenport's Cold Spring Harbor Station for Experimental Evolution, founded in 1904, expanded to include the Eugenics Record Office in 1910 with the mission to collect information about the genetic quality of the population of the United States for eugenic purposes; Harry H. Laughlin, "The Socially Inadequate: How Shall We Designate and Sort Them?" *American Journal of Sociology* 27 (1921): 54–705.

<sup>&</sup>lt;sup>74</sup> Charles B. Davenport, "Importance of Heredity to the State," in *Proceedings of the Quarterly Conference of the Minnesota State Board of Control* 12 (1912): 23–51.

<sup>&</sup>lt;sup>75</sup> For a discussion of Henry Goddard's study of the Kallikak family, see Reilly *The Surgical Solution*, 20–22.

servants. The first question from the Minnesota audience after Davenport's address was about the relative contributions of heredity and environment to human development, to which he replied that mentally defective children attain the appearance of good manners, but "no fundamental change of character" results from their exposure to a good environment. He cited the propensity of American Indian girls at boarding schools to return home and "fall at once, as if they fitted perfectly, into the conditions of the tribe, and become like the other squaws." Julian A. Dubois, a physician from Sauk Center, challenged Davenport, stating that precise measuring instruments do not apply to the mind and that genius is always haphazard. John A. Ryan, of the Saint Paul Roman Catholic Seminary, took exception to extrapolating from inherited mental defects to inherited moral defects. In response, Davenport argued that,

Young girls brought into the institutions where the best of Christian environment constantly surrounds them, break through every restraint and barrier which is afforded them in order to get out and hunt up some man to go off with them. And we find that not merely the individual, but their mothers and their grandparents and other relatives have had the same impelling instincts, have had the same uncontrollable instincts."

At the November 1925 quarterly meeting, the State Board of Control heard a lecture delivered by George Higgins of the Mayo Foundation about new discoveries in genetics.<sup>78</sup> They were interested because their institutions cared for hundreds of residents whom they had come to believe were genetically impaired. Higgins's educated listeners seemed to struggle to comprehend the level of detail of what he told them about genetic

<sup>&</sup>lt;sup>76</sup> Davenport, "Importance of Heredity to the State," 35–36.

<sup>&</sup>lt;sup>77</sup> Davenport, "Importance of Heredity to the State," 50.

<sup>&</sup>lt;sup>78</sup> George Higgins, "Heredity," in *Proceedings of the Quarterly Conference of the Minnesota State Board of Control* 25, no. 2 (November 8, 1925): 4–17.

science.<sup>79</sup> When he asked for questions and comments from the audience, they declined to say anything, citing lack of knowledge about genetics. What they stated that they did understand was the importance of good heredity to the state and the need for society to "secure its own improvement" through genetics.<sup>80</sup>

## The Political Setting for Minnesota's Eugenic Movement

Minnesota's political history provides context for its eugenics movement. In the United States around the turn of the twentieth century, professional people and civic leaders in small towns and cities realized that a few newly rich families and powerful corporations had suddenly come to dominate their lives and that they had lost their ability to control their local cities. Their anger about more powerful and distant economic and political forces having usurped their power increased as they encountered crowds of immigrants, pollution, blight, labor unrest, corruption, and economic turmoil. In reaction, a movement called Progressivism arose that hoped to reform the nation and restore it to its seemingly lost state of grace. The major strategies favored by the Progressives were to improve and perfect people through the application of scientific knowledge and society through governmental intervention and control. These lofty intentions were sometimes incongruent with the Progressive tendency for conservative nostalgia and resistance to change, but they contained the belief that allowing nature to take its course in biologic systems, the marketplace, or human society, was not acceptable. Eugenicists and

<sup>&</sup>lt;sup>79</sup> Peter S. Harper, *A Short History of Medical Genetics* (New York, NY: Oxford University Press, 2008), 77–9. William Bateson named the field of genetics in 1905, and Wilhelm Johannsen named the gene, phenotype, and genotype in 1906.

<sup>&</sup>lt;sup>80</sup> Comments from the audience following Higgins, "Heredity," (1925).

<sup>&</sup>lt;sup>81</sup> Richard Hofstader, The Age of Reform: Bryant to FDR (New York, NY: Vintage Books, 1955).

Progressives shared that desire to strive for perfection, including in human beings, and often turned to legislation for the means to achieve it.<sup>82</sup>

Political ferment and opposition to corporate domination swirled in Minnesota and the Upper Midwest during the first two decades of the twentieth century and was not limited to issues of heredity. Farmers continued to distrust railroads, banks, and corporations. Iron miners in northern Minnesota remained bitter about their brutal mistreatment during the strike of 1916. In North Dakota, a socialist–agrarian movement called the Non-Partisan League gained control of the Republican Party in the summer of 1916 by organizing farmers to vote for its candidates in the primary election. The Non-Partisan League took over the government of North Dakota in the November election. In 1917, the League moved its headquarters to St. Paul to duplicate its feat.

The Republican establishment in Minnesota was prepared for the challenge from the Non-Partisan League and never lost dominance. Joseph A. A. Burnquist (1879–1961), the conservative Republican governor elected in 1916, recognized the threat facing him and his party in the next election. The legislature and the governor reacted in 1917 by establishing the Commission of Public Safety, a wartime board to promote loyalty and cohesion. It was packed with conservative Republicans appointed by Burnquist. The Commission existed as an executive branch extra-legal organization outside the constitutional arrangements for governance and legal power, modeled on the State Board of Health's power to act in an emergency to protect the public health. It therefore had the authority to do anything deemed necessary to assure that Minnesota's citizens were loyal

 $<sup>^{82}</sup>$  Donald K. Pickens,  $\it Eugenics$  and the  $\it Progressives$  (Nashville, TN: Vanderbilt University Press, 1968), 3.

to the United States and that the state's resources were properly applied to the war effort.

Its real purpose, however, was to destroy the Non-Partisan League and other challenges to the established conservative order.

The Commission on Public Safety first cracked down on alleged pro-German sympathizers in the large immigrant community, along with associated pacifists and war critics. It removed the mayor of New Ulm from office for asking at a public rally that German-Americans not be forced to fight on German soil. In another anti-German measure, the Commission strictly enforced sedition laws that made it a crime to advocate that men not enlist in the army. Next, the Commission members accused the leaders of the Non-Partisan League of sedition and denied permits for meetings and rallies. Some League officials were thrown in jail. In the 1918 Republican primary, the Non-Partisan League candidate, Congressman Charles Lindberg, Sr. (1859–1924), was threatened with violence and death on the campaign trail. He narrowly lost the primary election to Burnquist by 40,000 votes. Supporters of Lindberg were driven out of the party amidst charges of disloyalty to the United States. 83 The Commission on Public Safety forces reserved their most drastic actions for left-wing activists, raiding the Minneapolis headquarters of the International Workers of the World (the Wobblies) and sentencing 101 men up to twenty years each in prison for disloyalty.

After World War I, rural and urban political opponents of the ruling order regrouped as the Farmer–Labor Alliance, a grassroots educational and social self-help

<sup>&</sup>lt;sup>83</sup> Carl H. Chrislock, *Watchdog of Loyalty: The Minnesota Commission of Public Safety During World War I* (St. Paul, MN: Minnesota Historical Society Press, 1991), x.

network that also functioned as an opposition political party, the Farmer–Labor Party. 84 In 1922, Minnesota voters, reacting to the repression unleashed by the Commission on Public Safety, elected the Farmer–Labor candidate for the United States Senate, Henrik Shipsted, and defeated two Republican United States Representatives and ten Republican state legislators. 85 The shift of power away from the Republicans and toward the Farmer– Labor Party in the 1920s ignited the career of Floyd B. Olson (1891–1936), the charismatic Farmer-Labor politician who had been elected Hennepin County Attorney in 1922. He nearly succeeded in winning the election for Minnesota governor in 1924, losing because he failed to distance himself from a small communist-tinged minor party and was unable to quell rumors about womanizing being spread by the Republicans. When the economy collapsed in 1929, the Farmer–Labor Party offered an alternative to the Republican political establishment in Saint Paul, the urban elites, the railroads, and the banks. In the election of 1930, Olson won the governorship and the Farmer–Labor Party took over Minnesota's government, except for the Minnesota Senate. They held power for eight years. The charismatic and popular Olson was re-elected twice before dying in office of cancer in 1936 at the age of 45. But even before his death, the Farmer— Labor Party's strength had eroded severely after the party platform in 1934 demanded an end to capitalism. The Democratic Party led by Hubert Humphrey (1911–1978) absorbed the Farmer–Labor Party in the 1940s.

Minnesotans in the mid-1920s when eugenics came to prominence had therefore experienced two strong and opposite political traditions in action. One was that of the

<sup>&</sup>lt;sup>84</sup>George H. Mayer, *The Political Career of Floyd B. Olson* (Minneapolis, MN: The University of Minnesota Press, 1951), 25.

<sup>85</sup> Chrislock, Watchdog, 330.

state government forcefully intruding into the lives of citizens through the extra-legal, quasi-governmental Commission on Public Safety. The second was the opposite tradition of collective action and cooperative self-help movements that strove to use government to protect people from the abuses of capitalism.

Charles Dight, Minneapolis physician, former socialist, and founder and leader of the eugenics movement in Minnesota in the 1920s, sympathized with Floyd B. Olson in his fight against the Republicans in 1924, saying that,

The Farmer Labor party movement was undoubtedly overwhelmed a year ago by the vote of morons in Minnesota. The masters of industry know how to swing them into line in an emergency and they will no doubt repeat it again and again. <sup>86</sup>

Dight's analysis reflected his left leaning political views and dim view of the mental capacity of the average voter.



Figure 2. Charles Freemont Dight. (Minnesota Historical Society)

 $<sup>^{86}</sup>$  Charles Dight to George R. Kirkpatrick, December 25, 1925, box 3, Dight Papers, Minnesota Historical Society.

Minnesota's dichotomous traditions of brutal governmental force on the one hand and powerful collective citizen action on the other might have each contributed to the acceptance of controlling human heredity through sterilization as a public responsibility in 1925. The actions of the Commission on Public Safety during the World War I were so radical that the eugenic strategy to surgically sterilize the feeble-minded might not have seemed drastic. Although still in control of the Legislature in the mid-1920s, the chastened and retreating Republicans showed support for progressive, mainstream causes such as allowing surgical sterilizations, the first tax on iron ore, and the first state income tax. The law allowing the sterilizations was also compatible with Farmer–Labor Party members' interests in self-reliance for immigrant and working families who did not have the means to care for children with disabilities and had no access to legal birth control.<sup>87</sup>

## **Eugenic Sterilization Debate in Minnesota in the Early 1920s**

In the early 1920s, Minnesota, unlike twenty-four other states including its four immediate geographical neighbors, had no law that allowed surgical sterilization. <sup>88</sup> In 1920, the State Board of Control invited the superintendent of the Wisconsin Home for Feeble-Minded, physician A. L. Beier, to speak to them about Wisconsin's sterilization measure. Beier cautioned them that because the birth rate among the less intelligent, especially the feeble-minded, was high, and because more intelligent citizens were choosing to have fewer children, "race degeneracy" was a serious threat. Under the 1917 law, Wisconsin officials had authorized the sterilization of seventy-six individuals and had encountered no complications or apparent adverse mental or physical changes in the

<sup>&</sup>lt;sup>87</sup> The Minnesota Motherhood Protection League was founded in 1928.

<sup>&</sup>lt;sup>88</sup> Reilly, *The Surgical Solution*, 46; Largent, *Breeding Contempt*, 72.

subjects. The sixteen teenage boys selected for sterilization had manifested "strong or abnormal sexual propensity, a faulty heredity, superficial brightness, and a strong tendency to elope." Girls chosen for sterilization had been "higher types who showed marked abnormal heredity, licentious temperament, decided sexual irregularities, and a number who had already given birth to illegitimate or defective offspring." One of the women had produced seven illegitimate children, all of whom were wards of the state. <sup>89</sup> The discussion among the audience after Beier's talk revealed differences of opinion about sterilization. Some opposed it because they believed that the operation would lead to promiscuous sex and the spread of venereal diseases. Others thought that fear of pregnancy did not affect sexual behavior anyway, especially for men. A Roman Catholic priest objected to sterilization, including vasectomy, as a "grave mutilation" of the human body, a characterization with which Beier forcefully disagreed. <sup>90</sup> A sterilization law similar to Wisconsin's was soon to be enacted in Minnesota.

Elsewhere in the United States, sterilization laws had faced obstacles. The first challenges were legal. For example, in 1913, the New Jersey Supreme Court ruled that its two-year-old law allowing involuntary sterilization was unconstitutional because it denied equal protection to institutionalized wards of the state. In 1918, the United States District Court in Nevada invalidated that state's sterilization law because it considered

<sup>&</sup>lt;sup>89</sup> A. L. Beier, "The Operation of the Wisconsin Sterilization Law," in *Proceedings of the Quarterly Conference of the Minnesota State Board of Control* 19, no. 4 (May1920): 7–23.

<sup>&</sup>lt;sup>90</sup> Comments from audience following Beier's lecture, 14 and 19.

<sup>&</sup>lt;sup>91</sup> Reilly, *The Surgical Solution*, 101. Twenty-seven states had active sterilization programs in 1932.

The second obstacle was adverse public opinion. Voters in Oregon, for example, repealed the state's 1913 involuntary sterilization law the same year that the legislature passed it. The third obstacle was opposition from the Roman Catholic Church, whose leaders condemned sterilization along with birth control, and divorce. Church doctrine held that interfering in human reproduction was morally offensive, lacked spiritual dimension, mutilated important organs of the body, and was unnatural and immoral. <sup>93</sup> The condemnation of sterilization became official doctrine in 1930 with Pope Pius XI's (1857–1939) encyclical, *Casta Connubi*, along with its prohibitions on abortion, birth control, and the "false liberty and unnatural equity" of the "New Woman."

# **Minnesota's Eugenics Movement** 95

The Minnesotan who almost single-handedly created the state's eugenics movement and who championed the drive for the 1925 sterilization law was the previously mentioned Charles Freemont Dight (1856–1938), Minneapolis physician, former instructor at the University of Minnesota Medical School, long-standing insurance company medical director, and two-term Socialist alderman. <sup>96</sup> In 1922, he started to write pamphlets such as "Human Thoroughbreds—Why Not?" to promote eugenics and mailed

 $<sup>^{92}</sup>$  Frances Oswald, "Eugenical Sterilization in the United States," *American Journal of Sociology* 36, no. 1 (1930): 65–73.

<sup>&</sup>lt;sup>93</sup> Daniel J. Kevles, "A Coalition of Critics," in *In the Name of Eugenics*, 113–28.

<sup>&</sup>lt;sup>94</sup> David M. Kennedy, *Birth Control in America: The Career of Margaret Sanger* (New Haven, CT: Yale University Press, 1970), 150.

<sup>&</sup>lt;sup>95</sup> Neal Ross Holtan, "Breeding for Brains: Eugenics, Physicians, and Politics in Minnesota in the 1920s," (University of Minnesota, M.A. 2000).

<sup>&</sup>lt;sup>96</sup> Evadene Burris Swanson, "A Biographical Sketch of Charles Fremont Dight, M.D.," in Dight Institute *Bulletin no. 1*, (1943), 8–22; Gary Phelps, "The Eugenics Crusade of C. F. Dight," *Minnesota History* 49 (1984): 99–115.

some of them along with his plans to start a eugenics society in Minnesota to the Eugenics Record Office at Cold Spring Harbor, NY. Dight received a response from Harry H. Laughlin (1880–1943), the assistant director, who wrote, "Permit me to acknowledge the receipt of your letter and of your very interesting brochure on the subject of 'Human Thoroughbreds.' I have examined the study with much interest and trust that the foundation which you are developing will be fortunate indeed." Dight promised that "anything of value that comes from such work here shall reach your office. He also received a letter from Laughlin's boss, Charles Davenport, following up on the same communication. Davenport advised Dight,

I have also been interested to learn of your interest in eugenics and your purpose to establish a eugenic foundation in Minneapolis. . . . Education probably makes a greater appeal than research. Nevertheless, we must know before we teach and the acquisition of knowledge is slow and expensive. <sup>99</sup>

Dight responded, "You have well said that 'we must know before we teach.' My feeling is that if we wait until we know it all before we begin to teach, we never will begin." <sup>100</sup>

On the evening of November 15, 1922, Dight called together a group of Minneapolis citizens to discuss eugenics. <sup>101</sup> Catheryne Cooke Gilman <sup>102</sup> (1880–1954), Executive Director of the Women's Cooperative Alliance, hosted the meeting in her

<sup>&</sup>lt;sup>97</sup> Laughlin to Dight, May 2, 1922, box 7, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>98</sup> Dight to Laughlin, May 10, 1922, box 7, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>99</sup> Davenport to Dight, May 5, 1922, box 7, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>100</sup> Dight to Davenport, May 22, 1922, box 7, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>101</sup> Unattributed typescript, "A Brief Account of the Early History of the Eugenics Movement in Minnesota," undated, box 4, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>102</sup> Cynthia A. Hanson, "Catheryne C. Gilman and the Minneapolis Better Movie Movement," *Minnesota History Magazine* 51, no. 6 (1989): 202–16.

office. 103 Her consortium of women's organizations was dedicated to creating a safe environment for women and children and followed the slogan: "Make Minneapolis the Best City in America for Wholesome Family Life." 104 It drew attention to immorality, indecency, and lewdness, and attempted to force the government to take action against prostitution, venereal disease, sexual predators, indecent dancing, obscene literature, the high cost of living, sex crimes, salacious magazines, tobacco, alcohol, carnivals, and peepshows. 105 Catheryne Gilman's husband, Robbins Gilman, 44-year-old social worker and Director of the Northeast Neighborhood House, was also at the meeting. 106 The Gilmans had come to Minneapolis in 1915 after being accused of sheltering Wobblies during the New York labor riots two years earlier. 107 The other people in attendance at the Minneapolis meeting were Victoria McAlmon, 42-year-old teacher in the child guidance department of the Minneapolis Public Schools, Katharine Hattendorf, 31-yearold secretary to Mrs. Gilman, and Henry Nachtrieb (1857–1942), professor and head of the Department of Animal Biology at the University of Minnesota and the head of the university's museum. 108 The group agreed to form the Minnesota Eugenics Society with

Minutes of the Women's Cooperative Alliance executive committee and board meetings, November 16, 1922, box 23, Gilman Family Papers, Minnesota Historical Society. The minutes do not mention that Gilman had attended the eugenics meeting the evening before.

<sup>&</sup>lt;sup>104</sup> Catheryne Gilman, handwritten notes for an address to the Women's Cooperative Alliance Delegate Council, June 17, 1932, box 24, Gilman Family Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>105</sup> Lucile M. Kane, "The Gilman Family Papers," Social Service Review 29 (1965): 92–5.

Winifred Wandersee Bolin, "Heating Up the Melting Pot," *Minnesota History Magazine* (Summer 1976): 58–69.

<sup>&</sup>lt;sup>107</sup> Kane, "The Gillman Family," 92.

<sup>108 &</sup>quot;A Brief Account of the Early History."

Dight as its president.<sup>109</sup> The organization's purpose, as stated in its promotional brochure, was "to spread abroad knowledge of the laws of heredity and the principles of eugenics in order to promote RACE BETTERMENT, and to secure the passage and enforcement of eugenic laws to that end." It also sought to "prevent reproduction by the socially unfit wards of the state and others who would transmit serious mental defect or disease to their offspring and who, as such, are a menace to the hereditary capacities of future generations." <sup>110</sup>

In 1923, Dight wrote Laughlin,

I am obliged indeed for the copy of your book, *Eugenical Sterilization in the United States*, received two days ago. It seems the book placed in the hands of legislators, judges, physicians, and progressive people should lead to legislation that will secure that race betterment to which eugenicists look.<sup>111</sup>

Laughlin's book, the first comprehensive account of sterilization in the United States, impressed Dight as just what he needed to plan Minnesota's eugenic sterilization law.<sup>112</sup>

Dight's other policy initiative as the new president of the Minnesota Eugenics Society was to press Thomas Canfield, the manager of the Minnesota State Fair to promote a "Fitter Families Contest." Canfield had heard a presentation about eugenic family competitions at a meeting for fair managers in Chicago in 1923, but he was not

<sup>109 &</sup>quot;New Eugenics Society to Make Educational Drive–Minnesota Organization Opens Headquarters in Minneapolis," March 10, 1923, *The Minneapolis Daily Star*, box 4, Dight Papers, Minnesota Historical Society. The article listed C. F. Dight as president, Victoria McAlmon, treasurer, Henry F. Nachtrieb, secretary, and Robbins Gilman and Albert E. Jenks as members of the executive committee.

 $<sup>^{110}</sup>$  Brochure, "Relating to the Minnesota Eugenics Society, Organized 1923, Incorporated 1926," box 4, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>111</sup> Charles Dight to Harry H. Laughlin, January 19, 1923, box 7, Dight Papers, Minnesota Historical Society.

Harry H. Laughlin, *Eugenical Sterilization in the United States* (Chicago: Psychopathic Laboratory of the Municipal Court of Chicago, 1922).

impressed. He told Dight that he thought few people in Minnesota would volunteer their families for eugenic examinations. Canfield declined to organize the contest, ostensibly because of the fair's commitment to display a dental health poster competition in the limited space available.<sup>113</sup>

#### **Eugenics and the Medical Establishment**

Many of Dight's physician colleagues agreed with his eugenic ideas and the need for involuntary sterilization of the feeble-minded while others disagreed. Among the supporters were the physicians in charge at the School for the Feeble-Minded. The superintendent, physician G. C. Hanna, was convinced that "more than 90 percent of feeble-mindedness and epilepsy and about 75 percent of insanity are hereditary." Based on prevalence rates found in a 1919 Indiana survey, Hanna calculated that in Minnesota there were 41,250 feeble-minded, 7,750 insane, and 3,750 epileptic people, but he thought those estimates far too low because there were already 6,881 people in Minnesota's insane asylums. 114

D. E. McBroom, the senior physician at the School for the Feeble-Minded, presented his views about feeble-mindedness at a medical meeting in 1923. Of Goddard's three classes of the feeble-minded, namely idiots, imbeciles, and morons, McBroom was most concerned about the numerous "morons," sexually mature adults with the minds of children. McBroom feared the moron because,

 $<sup>^{113}</sup>$  Charles Dight to Thomas Canfield, February 4, 1924, box 5, Dight Papers, Minnesota Historical Society.

<sup>114</sup> Hanna, "The Menace of the Feebleminded."

<sup>&</sup>lt;sup>115</sup> Zenderland, "Measuring Minds." The designations of idiot, imbecile, and moron were clinical terms at the time that were based on Goddard's classification system for categorizing low levels of IQ.

[he] expresses himself well, but fails in adjusting himself to any complex environment in which logical reasoning is required. He has no thought of the future or of anything beyond the immediate consequences of his acts, yields easily to sex temptations, and is usually improvident and drifts into pauperism. <sup>116</sup>

Hanna shared McBroom's opinions about high-grade morons, calling them a special danger to the public because they were unrecognizable as feeble-minded but sexually available and therefore likely to reproduce. In Hanna's view, "One has to be a grinning idiot before the public notices his mental status. Yet these poor creatures do not escape the lust of the vicious." For that reason, Hanna considered the high-grade female moron as representing "a greater menace than the male," because she was able to blend into society and was likely to attract a husband, saying,

Many a youth destined to become a factor in the business or professional world is attracted to the pretty face of one of the morons who sit on the back seats in the high schools and smile out such sweet 'I don't believe I know' answers to all questions on the lessons."<sup>117</sup>

The underlying fear was that high-grade morons, especially women, would quietly and invisibly pass their hereditary feeble-mindedness to the next generation. J. M. Murdoch, the physician who replaced Hanna at Faribault in 1927, held a similar opinion and used infectious diseases as an analogy with feeble-mindedness, arguing that,

The fact that defective genes may be carried by normal persons is no reason why the propagation of congenitally defective persons should not be prevented, any more than the fact that some apparently healthy carriers of the bacilli of diphtheria or typhoid fever is no reason why quarantine regulations should not be enforced or why we should repeal our criminal laws because all criminals are not apprehended. 118

<sup>&</sup>lt;sup>116</sup> D. E. McBroom, "Feeble-mindedness," *Minnesota Medicine* 6 (1923): 639.

<sup>&</sup>lt;sup>117</sup>Hanna, "The Menace of the Feebleminded," 27.

<sup>&</sup>lt;sup>118</sup> J. M. Murdoch, "Heredity as a Factor in Feeble-Mindedness," in *Proceedings of the Quarterly Conference of the Minnesota State Board of Control* 28 (September 1928): 8–18.

The dean of the University of Minnesota medical school, Elias Potter Lyon, energetically supported Dight, his crusade for eugenics, and the proposed sterilization bill of 1925. Lyon consistently published, spoke, and taught about eugenics. During the 1920s, he maintained extensive personal relationships with like-minded leaders at the University of Minnesota regarding race, eugenics, and the university's mission of producing "ideal citizens." 119

R. M. Phelps, the director of the state hospital for the insane at St. Peter, did not agree with his colleagues at Faribault that criminality and feeble-mindedness were related. In a paper delivered at a medical meeting in 1924, he stated that ". . . a feeble-minded person may be either moral and conscientious, or immoral and criminal—and I would assert that the feeble-mindedness does not by any necessity or great probability cause criminality." <sup>120</sup>

As an organization, the Minnesota Medical Association (MMA) never took an official position on eugenics; the word did not appear in the record of its official proceedings of annual meetings from 1918 to 1930. The minutes were silent about the sterilization law of 1925, even though the delegates to the annual meeting that year debated the merits of other bills on such issues as chiropractic medicine and the training

Mark Soderstrom, "Weeds in Linnaeus's Garden: Science and Segregation, Eugenics, and the Rhetoric of Racism at the University of Minnesota and the Big 10, 1900–45" (PhD Dissertation, University of Minnesota, 2003). Other faculty who played a part in eugenics during the 1920s were Albert E. Jenks, Professor of Anthropology, and Willet M. Hays, Professor of Agriculture. On the folder of his photograph in the Lee Photographic Portrait Collection at the Minnesota Historical Society, Lyon recorded his politics as "Independent" and religion as "Presbyterian."

<sup>&</sup>lt;sup>120</sup> R. M. Phelps, "The Character and Relationship of Criminality, Delinquency and Feeblemindedness," *Minnesota Medicine* 9 (1926): 55.

<sup>&</sup>lt;sup>121</sup> The Minnesota Medical Association's original files of the records and minutes of the annual meetings from 1918 to 1930 are consistent with the proceedings published in *Minnesota Medicine*. On personal inspection of these files with the assistance of MMA staff member, Jane Philip, I found no additional notes or records of the proceedings that were not published in the journal.

of nurses in psychiatric hospitals.<sup>122</sup> Although eugenics was not explicitly mentioned at MMA meetings, its members read related papers in their journal, *Minnesota Medicine*. J. H. James, a physician from Mankato, decried the "total moral depravity" in reform schools and prisons and believed that adult violent criminals ought to be castrated. He stated, "For such depravity there are only the alternatives of annihilation, life confinement or emasculation; there is no reform." James wanted to curtail the potential propagation of these inmates by emasculating them,

a deterrent, efficient as any other known means, if not superior to even the death penalty, so frowned on by super-sensitive philanthropists. The voluntary deliberate criminal by his own willfulness and acts voluntarily deprives himself of any civic rights or sympathy. As long as he is unrepentant he is an enemy of society, the state and the nation.

James argued that criminality and feeble-mindedness ran together through the generations. Psychiatrist W. A. Jones, on the other hand, remarked on the difficulty of obtaining psychiatric histories of family members of the feeble-minded back more than a generation or two. In spite of that, Jones believed that feeble-mindedness was inherited as immutable genetic material, and that education and good environment could not change it. 124

Other physicians had reservations about the inheritability of feeble-mindedness, its connection with criminality, and the wisdom of using surgical sterilization to prevent transmission to the next generation. Lawson Lowrey studied hundreds of delinquent children at the University of Minnesota's Child Guidance Clinic. He found that a large

<sup>122</sup> Editorial, "The Legislative Committee," *Minnesota Medicine* 7 (1925): 314.

 $<sup>^{123}</sup>$  J. H. James, "As exualization: A Remedy for Crime and Criminality," *Minnesota Medicine* 9 (1926): 61.

<sup>&</sup>lt;sup>124</sup> W. A. Jones, "Care and Treatment of the Psychoneurotic," *Minnesota Medicine* 8 (1925): 578.

percentage of the children had serious medical conditions and poor habits, but only 14 percent of them tested as feeble-minded, with an additional 15 percent as borderline. "This number may not seem small, but in view of the sometimes expressed view that all problems in delinquency are related to feeble-mindedness, the smallness is emphasized."<sup>125</sup> Smiley Blanton, Minneapolis pediatrician, did not put stock in the research that claimed that mental defects were inherited. 126 He cited Abraham Myerson (1881–1948), Boston psychiatrist and critic of eugenics, to support his contention that the research on feeble-mindedness had been "uncritical and inaccurate." Blanton thought that intelligence tests were not adequate to determine if sterilization was justified and that other dimensions of the person's life needed to be taken into account to create a comprehensive psychiatric assessment and determination of intelligence. <sup>128</sup> Like Blanton, George N. Ruhberg, instructor in nervous and mental diseases at the University of Minnesota Medical School, thought that studies of generations of feeble-minded families had been over-dramatized by Goddard and others, and agreed that Myerson had seriously called their validity into question. According to Ruhberg, these studies rested on unspecified "social field workers who judged the capacity of the quick and the dead

<sup>125</sup> Lawson G. Lowrey, "The Medical Aspects of Behavior Problems in Children," *Minnesota Medicine* 8 (1925): 42. Lowrey was the Director of Minneapolis Demonstration Clinic No. 2 of the National Committee for Mental Hygiene.

<sup>&</sup>lt;sup>126</sup> Smiley Blanton, "Asexualization," *Minnesota Medicine* 9 (1926): 89.

<sup>&</sup>lt;sup>127</sup> Abraham Myerson, *The Inheritance of Mental Diseases* (Baltimore, MD: Williams & Wilkins, 1925).

<sup>128</sup> Smiley Blanton, "Mental Tests," in *Quarterly Report of the Minnesota State Board of Control* 24 (1925): 15–20.

running back to the revolutionary days." He noted that many causes of feeble-mindedness existed that were not hereditary. 129

Only a small number of Dight's medical colleagues joined him as members of the Minnesota Eugenics Society, and a handful of his most dedicated physician allies publicly supported him by writing letters to newspapers or to legislators favoring his sterilization bill. For the most part, Dight stayed clear of physicians and their organizations in his crusade for eugenics and involuntary sterilization.

## The Life of Charles Dight

Charles Fremont Dight was born in 1856 on a farm near Mercer, Pennsylvania, the youngest of six. He graduated second in his class at the University of Michigan Medical School in 1876. During the years 1883 to 1889 Dight worked at the American University of Beirut as professor of anatomy, physiology and hygiene, and he gained vivid impressions of life in a society different and less affluent than his. In a lengthy address to the Literary Society of Beirut in 1886 on "sanitary science," Dight observed that in medieval Europe during the Black Plague and in the modern Middle East, disease came to humans "either by inheritance or from our surroundings," but that some diseases can be prevented by eliminating filth, thereby "starving the germs with cleanliness." After returning to the United States, Dight took the position as professor of physiology and physician at Shattuck School in Faribault, Minnesota, a small military school for

<sup>&</sup>lt;sup>129</sup> G. N. Ruhberg, "Recent Progress in Psychiatry," *Minnesota Medicine* 9 (1926): 523–24.

Swanson, "A Biographical Sketch." Charles Dight's parents may have chosen his middle name to honor the first presidential nominee of the Republican Party in 1856, John Fremont.

<sup>&</sup>lt;sup>131</sup> Charles F. Dight, printed speech to the Beirut Literary Society, "Sanitary Progress," February 4, 1886, published privately, box 2, Dight Papers, Minnesota Historical Society, 1–20.

boys. 132 Few records remain from his two years at Shattuck, but there is no evidence that he had contact with the School for the Feeble-Minded.

Dight's marriage in 1892 at age 37 to physician Mary Alice (Minnie) Crawford
Dight, also a graduate of the University of Michigan, ended in divorce. 133 They met at the
University of Minnesota Medical School, where she obtained a second medical degree,
this time in homeopathic medicine. Charles Dight's personal papers contained no
mention of his wife or his marriage other than one letter written by Minnie Dight to
Charles Dight's brother. 134 The Dights moved to Portsmouth, NH, to practice medicine
in 1892. Charles Dight advertised his medical services on a pre-paid basis at the rate of
\$10 per year for one person, \$15 for two, \$20 for three, \$25 for a family of four, and \$3
for each person more than four. 135 Charles Dight left New Hampshire for New Orleans in
1893, and Minnie Dight remained in New Hampshire to practice medicine until her death
in 1923. 136 Charles Dight never remarried. From 1893 to 1896, Dight served as faculty
member and Dean of the medical school of New Orleans University, the Episcopal school
for African–Americans and whites. During his stay in New Orleans, Dight delivered a
lengthy talk to a women's group on the subject of heredity. It began, "Throughout all

<sup>&</sup>lt;sup>132</sup> H. R. Drummond, Principal, Shattuck School, to Swanson, January 22, 1942, box 1, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>133</sup> Minnesota State Board of Medical Examiners to Swanson, February 13, 1942, box 1, Dight Papers, Minnesota Historical Society.

 $<sup>^{134}</sup>$  Minnie Dight to George Dight, March 3, 1892, box 1, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>135</sup> Printed handbill, 1892, box 2, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>136</sup> Minnesota State Board of Medical Examiners to Swanson, February 13, 1942, box 1, Dight Papers, Minnesota Historical Society. Mary (Minnie) Dight was born in Canton, OH, in 1860, and graduated from the University of Michigan Department of Medicine and Surgery in 1884. She practiced medicine at Colebrook, New Hampshire and died there in 1923.

Nature there is one magnificent law in operation—the law of 'Like producing Like." The law governed "our physical, mental, and moral Natures, our likes and dislikes, our peculiarities, eccentricities, or habits, desires and appetites." <sup>137</sup>

Charles Dight moved to Minnesota permanently in 1897 to become professor of physiology at Hamline Medical School in St. Paul. After its medical department merged with the University of Minnesota Medical School, Dight taught pharmacology, assisted with laboratory work, and lectured to student nurses. The entire faculty resigned during a major reorganization in 1906, and Dight and a number of other instructors were not rehired. 139

Dight served as the Medical Director of the Ministers' Life and Casualty Union of Minneapolis from 1900 until he retired in 1933. The position was in tune with his political temperament, not because he was religious, but because the organization was a mutual benefit association and not for profit. The company job provided him with a steady income, an office, and a base of operations. The company job provided him with a steady income, an office, and a base of operations.

 $<sup>^{137}</sup>$  Charles Dight, typescript of speech, undated, box 2, Dight Papers, Minnesota Historical Society, 1–40.

<sup>&</sup>lt;sup>138</sup> Hamline University catalogue, 1899–1900, box 3, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>139</sup> Edgar D. Brown, retired chairman of the Department of Pharmacology, University of Minnesota Medical School, to Swanson, March 10, 1942, box 1, Dight Papers, Minnesota Historical Society.

 $<sup>^{140}</sup>$  Benjamin Drake, typewritten obituary of Charles Dight, box 1, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>141</sup> Swanson, "A Biographical Sketch," 11.

Swanson makes no mention of the possibility that Minister's Life retained material in Dight's files relevant to his work with them when his personal papers were sent to the Minnesota Historical Society in 1938.

Dight's fellow citizens in Minneapolis knew him for his unusual seasonal tree house built in 1912 on iron stilts. <sup>143</sup> Neighbors called it the birdhouse. The sign above the door read, "Truth Shall Triumph, Justice Shall be Law," a quotation from an anti-slavery sermon delivered in Boston by Theodore Parker in 1854. <sup>144</sup> In 1914, officials of the Socialist Party tapped Dight to run for Minneapolis City Council. He told a news reporter during the campaign that he did not seek to become a candidate. According to the reporter, socialist party members nominated him to run in the primary and he won." <sup>145</sup> His stump speech was fiery and impassioned, demanding public ownership of utilities, a job for everyone, and honest pay for honest work. Dight castigated the established parties as servants of the despotic industrial master class and promised to represent the workers in their struggle for justice, saying,

When the possession of the earth passes over to a few, it gives them unnatural and unwarranted power. A few have far more than they need, which ministers to their selfishness, not to say their cruelty, while the many do not have even the necessities of life. 146

After winning election, Dight worked in vain to establish public ownership of the Minneapolis street car system and other utilities. He met success with an ordinance requiring the pasteurization of milk sold in the city. To get the ordinance passed in 1916, Dight asked for help from medical school dean Elias P. Lyon, who wrote to him, "I note what you say in regard to the medical faculty helping the movement for the pasteurization

<sup>&</sup>lt;sup>143</sup> John A. Arnold, "12<sup>th</sup> Ward Aldermanic Candidate Has Dwelling among the Treetops," *Minneapolis Tribune*, October 4, 1914, box 8, Dight Papers, Minnesota Historical Society. The tree house at 4818 39<sup>th</sup> Avenue South was torn down in 1931.

<sup>&</sup>lt;sup>144</sup> Swanson, "A Brief Biographical Sketch," 9.

<sup>&</sup>lt;sup>145</sup> Arnold, *Minneapolis Tribune* October 4, 1914.

<sup>&</sup>lt;sup>146</sup> Charles Dight, typewritten speech, with handwritten marginal note "Talk given by me many times during campaign 1914 in which I was elected alderman in 12<sup>th</sup> ward, Mpls., Delivered later before the I.W.W.'s in Minneapolis and elsewhere," box 4, Dight Papers, Minnesota Historical Society.

of milk. When you get ready to begin the campaign let me know and I will write all members of the faculty requesting them to assist to the extent of their ability."<sup>147</sup> Dight left the Socialist Party in 1917 because he believed that it become too radical with its anti-war platform at the party's national convention. <sup>148</sup> In 1918, a few months before Dight retired from public office, his colleagues on the Minneapolis City Council created an enduring, tangible memorial to Dight by changing the name of south Minneapolis's Railroad Avenue to Dight Avenue. <sup>149</sup>

Charles Dight exchanged letters with an old Socialist friend who had moved from Minneapolis to Chicago. George Kirkpatrick, the organizing director for the Socialist Party's National Office, sent greetings and inquired about Dight's health. Dight responded with a description of his lobbying for an involuntary sterilization law, and Kirkpatrick replied that he agreed with Dight's "special work with respect to the mentally defective." Kirkpatrick facetiously suggested that Dight arrange to treat "moral morons," namely the oil trust, exactly as he proposed for the "psychological morons."

<sup>147</sup> Elias P. Lyon to Charles Dight, February 25, 1916, box 4, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>148</sup> Swanson, "A Brief Biographical Sketch," 12.

<sup>&</sup>lt;sup>149</sup> Personal communication, Dennis Morris, Public Works Department, City of Minneapolis, July 10, 2000, referring to Council *Proceedings* 44 (1918): 437.

Diane B. Paul, "Eugenics and the Left," in *The Politics of Heredity: Essays on Eugenics, Biomedicine, and the Nature–Nurture Debate* (Albany, NY: The State University of New York Press, 1998), 11–37.

<sup>&</sup>lt;sup>151</sup> George Kirkpatrick to Charles Dight, December 29, 1925, box 3, Dight Papers, Minnesota Historical Society.

Dight stayed in contact with his brother George, who died a pauper in a residential hotel in Seattle in 1930, and with his five nieces. He attended the Dight family reunion at the home of one of his nieces in Pennsylvania in 1928. Another niece and her husband, a physician, wrote to invite him to live with them in Pittsburgh for the winter. He declined because of his eugenic work in Minnesota. Dight made his eugenic ideas personal in comments about their son, his grandnephew, stating, "Isabelle's remark about young Galen not being a spoiled child leads me to say with most children that are spoiled the spoiling process began nine months before they were born."

Among his papers, Dight left an undated statement about religion typed on the back of a business envelope. It read, in full:

To pray and to say a grace that offers thanks is to assume belief in a God that hears and answers prayer and who gives attention to our emotions. Some people may believe in the existence of such a God. I do not. No one, the bible tells us 'hath at any time seen God.' Belief in him is pure superstition. No person knows anything about him. If he exists and has created man and is then so neglectful of human interests as to permit floods, and cyclones, famines and wars to destroy, as they do, helpless men, women and innocent children by the millions, then he is heartless, most cruel and as bad as the imaginary devil and should be damned eternally. To put trust in the orthodox Christian's God is foolish, contrary to reason, and ordinary observation. Nature is evidently the only God there is. To adjust ourselves to nature's laws and utilize them as best we can for human welfare is the best that man can do. In this way only can man make progress and be blessed. For me to seem as many do to place dependence

<sup>&</sup>lt;sup>152</sup> H. M. Todd, Manager, DeVille Hotel, to Charles Dight, telegram, May 14, 1930, box 1, Dight Papers, Minnesota Historical Society. George Dight died without the necessary \$60 for burial and had an unpaid hotel bill of \$125.

 $<sup>^{153}</sup>$  George Dight to Charles Dight, May 20, 1928, box 1, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>154</sup> Charles Dight to Isabelle Dight Hover, October 12, 1927, box 1, Dight Papers, Minnesota Historical Society.

<sup>155</sup> Charles Dight to Galen and Isabella Dight Hover, April 12, 1929, box 1, Dight Papers, Minnesota Historical Society.

on outside help to be secured by prayer, or praise or graces said would be hypocrisy. 156

For Charles Dight, nature's laws, not God's, were his only guide in life and offered humanity its only salvation.

## **Dight's Eugenic Crusade**

Once Dight embraced eugenics, he did so with dedication and conviction, holding steadfast for more than ten years and working for the cause of eugenics with enormous energy until he was in his late 70s. More than three hundred of his articles and letters extolling eugenics appeared in Minneapolis newspapers and other publications, and he wrote propaganda pamphlets and radio speeches that he delivered on the air himself. <sup>157</sup> In person, he must have been insistent about expressing his views. Years after his death, a staff member at the State Board of Control, Mildred Thomson, recalled that she had often escaped out a side door of the Board's offices during the 1920s to avoid lengthy discussions with Dight about eugenics. <sup>158</sup>

Charles Dight and members of the executive committee of the Minnesota Eugenics Society met on December 24, 1924, to plan their strategy for introducing and supporting a sterilization bill in the legislature's 1925 session. George G. Eitel, Minneapolis surgeon, and Walter E. List, superintendent of the Minneapolis General

<sup>&</sup>lt;sup>156</sup> Typewritten note, undated, box 3, Dight Papers, Minnesota Historical Society.

<sup>157</sup> Charles Dight, *Call for a New Social Order* (Minneapolis, MN: Argus Publishing Co., 1936). Part 2 consists of the texts of twelve weekly radio talks on heredity and eugenics broadcast by Dight from radio station WRHM during the fall and early winter of 1933. The owner of the station, Troy S. Miller, made no financial charge for use of the time.

<sup>&</sup>lt;sup>158</sup> Phelps, citing Mildred Thomson.

<sup>&</sup>lt;sup>159</sup> Minutes of the executive committee of the Minnesota Eugenics Society, March 8, 1926, box 4, Dight Papers, Minnesota Historical Society.

Hospital, agreed to write letters supporting the bill and to testify in its favor at legislative committee hearings. <sup>160</sup> Other sympathetic physicians, including D. E. McBroom and Charles Mayo, were less direct, relaying their support of the bill through the State Board of Control rather than the Eugenics Society. <sup>161</sup>

Frederick Kuhlmann, the director of research for the State Board of Control, thought that Dight's bill went too far because it proposed to take a census of the state's mentally defective residents, place their names on a list, and consider all of them for sterilization. Kuhlmann wanted the sterilization law to cover only inmates of the School for the Feeble-Minded and require authorization from authorities. With these changes, Kuhlmann supported the law, even though he had reservations that he described in a letter to Dight,

I do not think sterilization is the ideal method of prevention, and am opposed to its wholesale application to all hereditary defectives simply because they are defective. . . The law however would be very valuable to apply in cases where the moral training and possible guardianship is not likely to prevent reproduction, and marriage might be permitted after sterilization. <sup>163</sup>

Legislative committees amended Dight's proposed law along Kuhlmann's lines to stipulate that a person needed to have been institutionalized at Faribault for at least six months before sterilization and that there be examinations by physicians, permission from

<sup>&</sup>lt;sup>160</sup> Walter E. List to Dight, January 26, 1925, and George G. Eitel to the Committee of Public Welfare and Social Legislation of the House of Representatives, January 26, 1925, box 4, Dight Papers, Minnesota Historical Society. George G. Eitel, on the form he personally annotated in 1913 for the folder for his photographic portrait in the Lee collection at the Minnesota Historical Society, listed his politics as "Republican" and his religion as "Rationalist."

<sup>&</sup>lt;sup>161</sup> D. E. McBroom to Frederick Kuhlmann, January 23, 1925; Charles W. Mayo to Kuhlmann, January 26, 1925, box 5, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>162</sup> Kuhlmann to Dight, January 9, 1925, box 5, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>163</sup> Kuhlmann to Dight, January 9, 1925.

the individual to be sterilized and the kin, and authorizations from the superintendent of the school and the State Board of Control.

#### **Eugenic Surgical Sterilization in Minnesota Law**

In April 1925, the Eugenics Sterilization Law (Chap I54-HF469 of Minnesota Statute) passed the House of Representatives 86 to 37 and in the Senate 40 to 4. It took effect on January 1, 1926. The State Board of Control approved operations for six women with IQs between 57 and 71, and the women were sterilized on January 8th. One of the women was 41 years old, the rest were between 20 and 25. In accordance with the law, the women and next of kin or guardian (in one case, the State Board of Control) gave consent for surgery. They underwent pre-operative psychological examinations performed by Kuhlmann and medical examinations by one of the Faribault physicians. With Dight present as an observer, the surgical team in the operating room at the School for the Feeble-Minded consisted of George G. Eitel, prominent Minneapolis surgeon and supporter of eugenics, and David E. Stern, a resident surgeon at the University of Minnesota." <sup>164</sup>

A day later, on January 9, 1926, Dight, Eitel, and List met with Minnesota Governor Theodore Christianson and members of the State Board of Control in the governor's office to extol the successful sterilizations and to propose expanding the sterilization law to cover feeble-minded Minnesotans who did not reside at the School for the Feeble-Minded.<sup>165</sup> The three doctors urged that Minnesota emulate California in

<sup>&</sup>lt;sup>164</sup> "Records of Sterilization," leather-bound ledger book, each operative case on a separate page, 1000 cases total, Faribault State School and Hospital Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>165</sup>Anonymous typescript, "A Brief Account of the Early History of the Eugenics Movement in Minnesota."

adopting a broad and vigorous sterilization program for all feeble-minded residents of the state. List assured the Board of Control that his institution, the Minneapolis General Hospital, would assist in any way possible to support the sterilization laws. The governor and the board made no promises, but the members of the State Board of Control expressed appreciation for Eitel's donated services and appointed him chief surgeon to perform the sterilizing operations.

The pattern of sterilizations set in early 1926, six to ten young women per month, continued for the next ten years. <sup>167</sup> The leather-bound sterilization ledger book kept at Faribault filled up with entries showing that most of the women were of ages and IQs similar to the five younger women sterilized first. <sup>168</sup> The same small group of surgeons performed the sterilizations during the first ten years. George G. Eitel operated frequently in 1926 and 1927 before his death in 1928. <sup>169</sup> His nephew, George D. Eitel, along with A. L. Herman, and David Stern, performed nearly a thousand of the operations from 1926 to 1936. Between 1926 and 1938 the state of Minnesota sterilized more than twelve hundred inmates at Faribault, 1,078 women and 202 men. <sup>170</sup>

<sup>&</sup>lt;sup>166</sup> Phelps, "The Crusade of Charles Fremont Dight."

<sup>&</sup>lt;sup>167</sup> Engberg, "The Sterilization of Mental Defectives," 171.

<sup>&</sup>lt;sup>168</sup> Records of Sterilization. In 1926, there were 53 individuals sterilized; in 1927, 90; in 1928, 57; in 1929, 67; in 1930, 60; in 1931, 76; in 1932, 78; in 1933, 70; in 1934, 176; in 1935, 140; in 1936, 80.

<sup>&</sup>lt;sup>169</sup> "Dr. G.G. Eitel Dies Suddenly at Age of 69, Was Leader in Minneapolis Medical Science for 30 Years," *Minneapolis Tribune*, February 10, 1928.

<sup>&</sup>lt;sup>170</sup> Engberg, "The Sterilization of Mental Defectives in Minnesota," 171.



Figure 3. Ledger Book of Sterilization Cases at the School for the Feeble-Minded and Colony for Epileptics, Faribault, Minnesota, 1926–1936. (Minnesota Historical Society)

#### The Incorporation and Life of the Minnesota Eugenics Society, 1926–1938

In the spring of 1926, fresh from their legislative and surgical successes, Charles Dight and the other members of the executive committee decided to incorporate the Minnesota Eugenics Society. The new structure consisted of a large advisory council of 25 of the 150 members to elect officers and vote on new ventures. The Minnesota Eugenics Society desperately needed more loyal members to donate money for organizational and promotional expenses. The George G. Eitel pledged money to hire a public relations man to recruit members and raise money. Andrew Francis Lockhart,

<sup>&</sup>lt;sup>171</sup> Untitled typewritten document, May 12, 1926, box 5, Dight Papers, Minnesota Historical Society. Nearly all of the ninety members of the first council had traditional English names and all but a few were men.

<sup>172</sup> Typewritten document, "Financial Report," April 19, 1927, box 5, Dight Papers, Minnesota Historical Society. One donation was \$150, another 100, three 25, two 20, two 15, seven 10, the other 44 were \$3 or less. Thirty-one donors were designated as "Dr."; seven as "Rev."; two as "Judge," and 17 as Mr., Mrs., or Miss, including one state senator and one attorney.

<sup>&</sup>lt;sup>173</sup> Dight to George G. Eitel, November 12, 1926, box 4, Dight Papers, Minnesota Historical Society.

aged 27, was the man chosen by Dight and Eitel for the job. 174 Lockhart started work on September 9, 1926, at a salary of \$150 per month. He made appointments with businessmen, community leaders, lawyers, and politicians to persuade them to join the Minnesota Eugenics Society and donate money. Before long, it was obvious that no amount of work on Lockhart's part would raise even his own salary. Almost from the beginning, Dight was not happy with what he perceived was Lockhart's lack of diligence. In contrast, Lockhart's logbook documented his grueling schedule of letter writing and personal visits. In early November, Dight summarized a conversation between them about the young man's failure to raise enough money. Just before Thanksgiving, Dight notified Lockhart by letter that his salary was to be cut to \$100 per month or less, depending on his ability to raise it, and Lockhart immediately resigned in protest.

It is little wonder that Lockhart had complained about headaches and sore feet. He walked and rode streetcars to scores of appointments in Minneapolis only to be kept waiting needlessly, sometimes in view of the man he had an appointment to see. The businessmen treated him rudely and abruptly. Worst of all, some of them wanted to spend

<sup>&</sup>lt;sup>174</sup> Dight to Andrew Francis Lockhart, July 3, 1926, box 5, Dight Papers, Minnesota Historical Society.

 $<sup>^{175}</sup>$  Dight to George G. Eitel, November 12, 1926, box 4, Dight Papers, Minnesota Historical Society.

 $<sup>^{176}</sup>$  Charles Dight, small pocket ledger book, handwritten notes, 1926, box 4, Dight Papers, Minnesota Historical Society.

Andrew F. Lockhart, typed document clipped together with metal holders, "Daily Field Notes," September 7 to December 3, 1926, box 4, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>178</sup> Dight to Lockhart, November 15, 1926; Lockhart to Dight, November 30, 1926, box 4, Dight Papers, Minnesota Historical Society.

extensive time talking about eugenics, and then refused to donate any money.<sup>179</sup> After first failing to raise money from businessmen and lawyers, Lockhart tried physicians. He found that they divided equally among those who gave a bit of cash, those who were only interested in talk, and those who were firmly opposed to eugenics. Among those who showed interest, the most they agreed to donate was a dollar or two. The physicians most enthusiastic about eugenics seemed to be the Norwegian immigrants, but they were even less apt to donate money than their colleagues. Lockhart made note of which physicians were Catholics, sometimes approaching them for a donation but usually avoiding them on the basis of rumors about their opposition to eugenics. The effort must have worn severely on Lockhart's patience. Toward the end of his employment with the Eugenics Society, he confided to his log that the parents of one doctor who talked a long time and then refused to give any money "ought to have engaged in a little eugenics in his case." A. F. Lockhart eventually became the respected editor of the labor newspaper, the *Minnesota Union Advocate*, from 1931 to 1956. <sup>181</sup>

While Lockhart failed in his struggle with reluctant donors, Dight had his own problems expanding the sterilization law beyond the School for the Feeble-Minded.

During the last half of the 1920s, Dight's biennial proposals to expand sterilization were quietly opposed by the State Board of Control and met no success in the legislature. <sup>182</sup> In December 1930, Dight destroyed all hope of achieving expanded sterilization legislation

<sup>&</sup>lt;sup>179</sup> Lockhart, 'Daily Field Notes."

<sup>&</sup>lt;sup>180</sup> Lockhart, "Daily Field Notes."

<sup>&</sup>lt;sup>181</sup> Obituary, the *Minnesota Union Advocate*, May 1, 1958, Lockhart Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>182</sup> Blanche L. La Du, chairperson of the State Board of Control, to Dight, March 19, 1930, box 6, Dight Papers, Minnesota Historical Society.

when he embarrassed his allies by putting their authorized signatures on a letter but failing to inform them that they also were signing on to an enclosed pamphlet that blasted the State Board of Control for obstructionism. Dight's eugenic campaign never recovered from that strategic blunder.

## Dight's Correspondence with Officials in Nazi Germany

The legacy of Charles Dight is still a lightning rod of negative opinion in Minnesota because of his correspondence with Adolf Hitler in the 1930s. Dight wrote a letter in 1933 to Hitler congratulating him on his election, and Hitler's staff's replied. Dight wrote again on August 1, 1933, saying,

I enclose a clipping from the Minneapolis Journal of Minnesota, United States of America, relating to, and praising your plan to stamp out mental inferiority among the German people. I trust you will accept my sincere wish that your efforts along that line will be a great success and will advance the eugenics movement in other nations as well as Germany. 185

Pasted onto the copy Dight's note to Hitler was the clipping of the newspaper letter to the editor to which Dight referred:

The report persistently comes from Berlin that congenital feeble-mindedness, insanity, epilepsy, and some other serious conditions that are inheritable are to be stamped out among the German people. Adolf Hitler is having broad and scientific plans formed for this. If carried out effectively, it will make him the leader in the greatest national movement for human betterment the world has ever seen. The world's two great

<sup>&</sup>lt;sup>183</sup> Richard Olding Beard to S. A. Stockwell, December 6, 1930, box 6, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>184</sup> Personal correspondence, Stefan Songstad at the Minnesota Historical Society, November 28, 2007. The letter from Dight to Hitler and the reply were misplaced at the Minnesota Historical Society for many years and thought to be lost or stolen, but they had been used in an exhibit in 1944 and misfiled in an unrelated collection, re-discovered by staff in the early 2000s.

<sup>&</sup>lt;sup>185</sup>Dight to Hitler, August 1, 1933, box 8, Dight Papers, Minnesota Historical Society.

needs are cooperation in industry for social good and biological race betterment through eugenics. CF Dight, Minneapolis. <sup>186</sup>

The German Law on Preventing Hereditarily Ill Progeny, influenced by the eugenics laws in California and the 1922 model sterilization law written by Harry Laughlin, was passed by the Nazi state on July 14, 1933, but was not put into effect until January 1, 1934. It was slightly more moderate than Laughlin's model in that it did not allow for the sterilization of criminals or alcoholics. The Law against Dangerous Habitual Criminals, passed on November 24, 1933, addressed these groups. <sup>187</sup> Dight's support for Hitler's sterilization plans was not unusual among eugenicists in the United States in 1933. Leon F. Whitney, speaking on behalf of the American Eugenics Society, similarly claimed in letters to newspapers that Hitler's race policy showed courage and leadership. <sup>188</sup>

# The Death of Charles Dight

Charles Dight died June 20, 1938 at age 82 from heart disease. His body was cremated at Lakewood Cemetery in Minneapolis, and his ashes released November 4, 1939, to Benjamin Drake, his lawyer, friend, and executor of his estate. Evadene Swanson, Dight's biographer, organized and sorted his personal papers at the Minnesota Historical Society in 1941. As preparation, she wrote to many of the schools, organizations, and individuals with which he had been associated. Charles Davenport,

<sup>&</sup>lt;sup>186</sup>Dight, letter to the editor, "Looking to Hitler," *Minneapolis Journal* July 28, 1933.

<sup>&</sup>lt;sup>187</sup>Stefan Kuhl, *The Nazi Connection: Eugenics, American Racism, and German National Socialism* (New York, NY: Oxford University Press, 1994), 51.

<sup>&</sup>lt;sup>188</sup> Kuhl, 46.

<sup>&</sup>lt;sup>189</sup> State Board of Medical Examiners to Swanson, February 2, 1942, box 1, Dight Papers, Minnesota Historical Society.

<sup>&</sup>lt;sup>190</sup> Personal communication, manager of Lakewood Cemetery, July 3, 2000.

<sup>&</sup>lt;sup>191</sup> Swanson, "A Brief Biographical Sketch," 20–23.

contacted in 1942 for his memories, stated that he did not remember Dight as an important person in the eugenics movement, saying only, "The principal contribution which Dr. Dight made was, in my personal opinion, in presenting clearly a plea for eugenics. All such presentations have their value but it is hard to estimate it quantitatively." <sup>192</sup>

Dight's great contribution to the history of genetics and public health consisted instead of his bequest to the University of Minnesota to establish and support the Dight Institute for Human Genetics. Charles Dight understood that more knowledge was needed to make his vision of a genetically healthy Minnesota occur. Even though surgical sterilization had been applied to a relatively few individuals, the sterilization law set a precedent for state action to improve the genetic quality of the population. Because of doubts among opinion leaders and elected officials about the soundness of the science to support surgical sterilization of the feeble-minded, Dight had not been able to expand eugenic interventions beyond a limited population of inmates at the School for the Feeble-Minded. Through his last will and testament, Dight intended to insure that knowledge about human genetics would become so widely known and broadly supported that Minnesotans would use it as a tool to improve the quality of their collective heredity.

 $<sup>^{192}</sup>$  Charles B. Davenport to Evadene Swanson, February 5, 1942, box 1, Dight Papers, Minnesota Historical Society.

#### **CHAPTER 3**

# **Intellectual Foundation for Human Genetics in Minnesota:**

## The Dight Institute and Sheldon Reed

The Dight Institute was one of the roots of what may be expected to become a massive tree, sheltering the knowledge of human genetics which will certainly be of vital importance to the well being of future generations as well as being of benefit to many persons at present. <sup>193</sup>

—Sheldon C. Reed, 1978

When Charles Dight died in 1938, he created a legacy by leaving his estate to the University of Minnesota for a human genetics institute. In accepting the terms of his will, the university agreed to establish an institute for "the study and promulgation of genetics as it applies to man." The Charles Fremont Dight Institute for the Promotion of Human Genetics, later shortened to the Dight Institute for Human Genetics, came into existence in 1941. Following the dictates of the will, the Dight Institute's work consisted first of the academic components of education, service, and research, and later, the non-academic tasks of publicizing human genetics in the mass media and forming an advocacy group, the Minnesota Human Genetics League.

Charles Dight formulated the idea of an institute for human genetics, one with a strong emphasis on eugenics, in his last will and testament dated March 1, 1927.<sup>195</sup> Given the existence of the Carnegie Institution's Eugenics Record Office (ERO) at Cold Spring Harbor, New York, established in 1904, the idea of an institute was not original to Dight.

<sup>&</sup>lt;sup>193</sup> Sheldon C. Reed, Dight Institute *Bulletin no. 15*, (1978).

<sup>&</sup>lt;sup>194</sup> Charles F. Dight, will, March 1, 1927, box 2, Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>195</sup> Charles F. Dight, will.

The innovative aspect of Dight's vision was that the promotion of human genetics would occur within the context of a major university in the United States. <sup>196</sup> The new institute would be based not only on education, research, and service but also would advocate for human betterment by means of a eugenics society, and Dight compelled the University of Minnesota to accept every stipulation in his will or forfeit his bequest. His will, witnessed by eugenics supporter, surgeon, and friend, George G. Eitel, gave \$100 to each of Dight's close relatives. Dight bequeathed to the Minnesota Historical Society (MHS) his personal papers, including the booklet, "Human Thoroughbreds, Why Not?" for which he provided \$2,000 to print and distribute. He set aside additional money to publish another of his manuscripts, "The Way Out," his treatise on constructive socialism. After these small bequests, Dight left the rest of his estate, approximately \$100,000, to the University of Minnesota for a human genetics institute. <sup>197</sup>

Dight's will put stringent conditions on the University of Minnesota. The money had to be invested in non-speculative securities and the earnings used to support an institute to "promote biological race betterment in human brain structure and mental endowment and therefore in behavior by spreading abroad in the largest way possible, knowledge of the laws of heredity and the principles of eugenics and by promoting the application of eugenic measures." In addition, the university was required to teach heredity and eugenics to its students and to educate the public on these topics through open lectures and articles in the popular press. These strategies were consistent with

Daniel Kevles, "Charles Davenport and the Worship of Great Concepts," in *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (Cambridge, MA: Harvard University Press, 1985), 41–56.

About \$1.5 million in 2009 dollars, http://www.measuringworth.com, accessed January 28, 2011.

Dight's experience as a medical school professor, newspaper and magazine writer, and radio orator. He stipulated that the university would "aid in inaugurating and in carrying out a wise eugenic program; to assemble and preserve records of good and bad family strains to which interested parties may refer as an aid in promoting eugenic marriages and measures; to form eugenic societies." And, he specified that the university would "maintain a place, if practicable, for consultation and advice on heredity and eugenics and for rating of people, first, as to the efficiency of their bodily structure, second as to their mentality; third as to their fitness to marry and reproduce." The will required an annual written report summarizing progress in meeting the terms of his bequest. If the University of Minnesota declined Dight's gift, the executor would recruit the largest university in the United States that agreed to the will's provisions. In a codicil dated July 30, 1936, Dight specified that his alma mater, the University of Michigan, would have first right of refusal after Minnesota. His amended will also contained a deadline for the University of Minnesota to accept the terms within six months of his death.

Charles Dight died in 1938, and the University of Minnesota accepted the bequest with its all its provisions. Its first director, Clarence P. (Pete) Oliver (1898–1991), aided by an advisory committee appointed by the president of the University of Minnesota, established the institute according to Dight's wishes. On June 13, 1941, the advisory committee named by the University of Minnesota president reviewed the will and approved a plan for the institute. The Dight Institute for the Promotion of Human Genetics opened on July 1, 1941.

<sup>&</sup>lt;sup>198</sup> Committee report, June 13, 1941, box 2, folder "Dight Institute Committee and Reports, 1941–57," Dight Institute Papers, University of Minnesota Archives.

The advisory committee and director compensated for the outdated and embarrassing eugenic language in the will by reframing Dight's requirements for a focus on eugenics to one on human genetics. For example, the eventual development of "genetic counseling" in 1947, the application of human genetic knowledge for medical purposes, was considered to fulfill the will's stipulations, "To Promote Biological Race Betterment—betterment in Human Brain Structure and Mental Endowment and therefore in Behavior," and to "maintain a place for consultation and advice on heredity and eugenics and for rating people, first, as to the efficiency of their bodily structure; second as to their mentality; third as to their fitness to marry and reproduce." 199

## **Early Years of the Dight Institute**

The Dight Institute was one of the first programs devoted entirely to human genetics in a university in the United States. Oliver, trained as a geneticist under H. J. Muller (1890–1967) at the University of Texas, had come to the University of Minnesota in 1932 to join the Department of Zoology. At the time, the field of human genetics existed only as a side interest among a few individuals trained in animal genetics who saw potential in applying genetic knowledge to humans. Even most geneticists thought that human genetics was too complicated to understand and impossible to research. Oliver tried during the 1930s to interest the University of Minnesota's medical school faculty, primarily the pathology department, in human genetics, but he encountered fatalism and disinterest about genetic diseases among the physicians. With the Dight

<sup>&</sup>lt;sup>199</sup> Sheldon C. Reed, "A Short History of Genetic Counseling," in Dight Institute *Bulletin no. 14* (1974).

<sup>&</sup>lt;sup>200</sup> Peter S. Harper, *A Short History of Medical Genetics* (New York, NY: Oxford University Press, 2008).

bequest, Oliver was in better position to promote the study of human heredity than as a geneticist in the Zoology Department.

Oliver's experience with the skeptical physicians had taught him that he needed solid support from many parts of the university in order for his human genetics institute to succeed. The first step to gain wide support within the university was to maintain the advisory committee composed of high-ranking University of Minnesota faculty and chaired by the Dean of the Graduate School, Theodore Blegen (1891–1969). The other members were: Peter J. Brekhus, chairman of the Division of Oral Diagnosis in the School of Dentistry; Eric K. Clarke, Director of the Psychiatric Clinic for Children; Stuart W. Cook, Head of the State Psychological Services; Donald G. Paterson, Professor of Psychology; Dwight E. Minnich (1890–1966), Professor and Head of the Zoology Department; and ex-officio member Clarence P. Oliver. Minnich later succeeded Blegen as the advisory committee's chairman and led the advisory committee for many years. <sup>201</sup> Gaylord Anderson, who became the dean of the new School of Public Health in 1954, served on the committee during the early 1950s. <sup>202</sup>

<sup>&</sup>lt;sup>201</sup> Clarence P. Oliver, in Dight Institute *Bulletin no. 1* (1942).

<sup>&</sup>lt;sup>202</sup> List of members of the Advisory Committee for the Dight Institute, 1953–1954, box 1, folder "Advisory Committee," Dight Institute Papers, University of Minnesota Archives.



Figure 4. Dwight E. Minnich, 1958. (University of Minnesota Archives)

The first components of the Dight Institute's work focused on the three academic missions mentioned in Dight's will: education, research, and service. Oliver inaugurated the educational mission with new courses of instruction in human genetics for undergraduate and graduate students. According to Dight's wishes, he set up an annual public lecture by an invited internationally renowned leader in human genetics. Oliver honored Dight's charge to educate the "intelligent public" about human genetics by giving talks to almost any professional or lay audience in Minnesota that invited him. Oliver, and Sheldon C. Reed, his successor, were deluged with requests from a wide variety of professional organizations, community groups, and social clubs to give talks about human heredity. Inquiries about genetics came from families wanting to know about specific genetic situations, officials at adoption and child welfare agencies

 $<sup>^{203}</sup>$  Clarence P. Oliver, in Dight Institute Bulletin no. 1 (1941).

concerned about racial issues, staff at state hospitals for the insane or mentally retarded regarding their patients, and counselors, clergymen, and health care professionals with questions about hereditary impairments.

As specified by Dight, Oliver began the tradition of writing an annual or biennial report of the Dight Institute's activities and achievements published as consecutively numbered bulletins, sent to the President of the University of Minnesota and distributed as small booklets. Oliver wrote the initial bulletin in 1943, the first of a series of sixteen. *Bulletin no. 1* set the pattern for those that followed, with information about the Dight Institute's finances and its work in research, teaching, and service. *Pulletin no. 1* contained a lengthy biography of Charles Freemont Dight commissioned for the occasion. The Institute's director published bulletins approximately every two years. Subsequent bulletins contained supplements (either as prefaces or appendices) that celebrated individuals who served as advisors and benefactors, described aspects of the history of human genetics, discussed work done at the Dight Institute, and summarized various topics in human genetics. Oliver produced *Bulletins no. 1–5* and Reed *Bulletins no. 6–16.* Page 1979

In 1946 Oliver left Minnesota to start a human genetics institute at his *alma mater* in Texas, part of a growing trend to establish human genetic programs at universities. The

<sup>&</sup>lt;sup>204</sup> See Appendix A, Contents of the Dight Institute *Bulletins no. 1–18* (1943–1979).

Evadene Burris Swanson, "A Biographical Sketch of Charles Freemont Dight, M.D.," in Dight Institute *Bulletin no. 1* (1941).

<sup>&</sup>lt;sup>206</sup> The Minnesota Historical Society has a complete bound set of Dight Institute *Bulletins*. The University of Minnesota Archives holds manuscripts, both handwritten and typed, galley proofs, and published versions of various *Bulletins*, but not the complete set.

<sup>&</sup>lt;sup>207</sup> Sheldon C. Reed, in Dight Institute *Bulletin* no. 17 (1978).

first had been started at the University of Michigan in 1940, the second at the University of Minnesota in 1941 (the Dight Institute), and followed by eight at various other universities, including Texas, by 1955. 208 The advisory committee at the Dight Institute formed a search committee chaired by Minnich to find Oliver's replacement, ideally a man between 35 and 45 years of age to teach genetics in the Zoology Department half of his time and devote the rest to running the Dight Institute. <sup>209</sup> In addition the candidate needed to possess leadership potential to "meet people easily and effectively for he will have important relationships with many other parts of the University and with persons and agencies throughout the state." The field of potential applicants was limited because of the dearth of training opportunities for human geneticists at the time. Curt Stern (1902–1981), arguably the foremost American geneticist of the day, counseled Minnich that to his knowledge only James V. Neel, his former student at the University of Rochester, now at the University of Michigan's Human Heredity Clinic, possessed such qualifications. <sup>211</sup> After several months, the search committee selected Sheldon Clark Reed (1910–2003), a junior professor of zoology at Harvard University as Oliver's replacement.

<sup>&</sup>lt;sup>208</sup> Harper, *A Short History*, 278.

<sup>&</sup>lt;sup>209</sup> Dwight Minnich to Curt Stern, May 16, 1946, Curt Stern Papers, American Philosophical Society.

<sup>&</sup>lt;sup>210</sup> Minnich to Stern, May 16, 1946, Curt Stern Papers, American Philosophical Society.

<sup>&</sup>lt;sup>211</sup> Stern to Minnich, May 25, 1946, Curt Stern Papers, American Philosophical Society.

### **Reed Accepts the Dight Institute Directorship**

Sheldon Reed exemplified the few geneticists in the 1940s who moved from experimental animal genetics into human genetics. <sup>212</sup> In accepting the directorship of the Dight Institute, Reed took a career risk to concentrate almost exclusively on human genetics, a field of knowledge that was still in its infancy. He was lucky because knowledge in human genetics was about to explode. Reed recalled, "It gradually became clear to me that human genetics was more important than the mouse and Drosophila genetics which I had been working on, and that very little was being done in human genetics." <sup>213</sup> He specialized in the even narrower field of behavioral human genetics, concentrating on psychoses and mental retardation. <sup>214</sup>



Figure 5. Sheldon Clark Reed. (University of Minnesota Archives)

<sup>&</sup>lt;sup>212</sup> Harper, *A Short History*, 319–20.

<sup>&</sup>lt;sup>213</sup> Sheldon C. Reed to Kenneth M. Ludmerer, July 28, 1970, box 1, folder "Correspondence L," Dight Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>214</sup> V. Elving Anderson, "Sheldon C. Reed, Ph.D." (November 7, 1910–February 1, 2003): Genetic Counseling, Behavioral Genetics," *American Journal of Human Genetics* 73 (2003): 1–4.

A native of Vermont, Reed graduated from Dartmouth College in 1932 with a published paper on the genetics of harelip mice to his credit. Moving to Harvard University to study genetics under William E. Castle (1867–1962), he received his Ph.D. in 1935 and produced nine papers on the genetics of mice and rabbits, one of which compared his work on mice with humans affected by harelip. He spent brief periods of time with Sewell Wright at the University of Chicago and with Ross Harrison at Yale concentrating on the genetics of morphogenesis before accepting a position in 1940 on the faculty of Harvard University. Reed's research shifted toward the genetics of behavior, for example, identifying new species of fruit flies by characteristics such as frequency of wing beats in those early years. <sup>216</sup>

Sheldon Reed spent 1942 through 1945 in London as a civilian scientist with the Operations Evaluation Group in the Office of the Chief of Naval Operations of the United States Navy. While in England, Reed worked on technology issues and on obtaining information from captured German scientists. After the war ended, he returned to Harvard where he met and married Elizabeth Wagner Beasley, assistant professor of biology and war widow with one child, John Beasley. Sheldon and Elizabeth Reed had two other children, Catherine and William.

<sup>&</sup>lt;sup>215</sup> Sheldon C. Reed and George Davis Snell, "Harelip, a New Mutation in the House Mouse," *The Anatomical Record* 51 (1931): 43–50.

<sup>&</sup>lt;sup>216</sup> V. Elving Anderson, "Sheldon C. Reed".

Reed's voluminous papers at the University of Minnesota Archives include no mention of his experience with the United States Fleet and the British Admiralty other than invitations to reunions.

<sup>&</sup>lt;sup>218</sup> V. Elving Anderson, "Sheldon C. Reed".

<sup>&</sup>lt;sup>219</sup> V. Elving Anderson, "Sheldon C. Reed."

As Reed recalled, almost from his first hour on the job as director of the Dight Institute on August 18, 1947, he received requests from the medical school's pediatric clinic to advise the doctors about genetic abnormalities in patients and to counsel parents about the risk of bearing additional children with the same problems. That first morning he was summoned to the clinic to evaluate "a family in which four out of five children had some type of eosinophilia." In the afternoon he received a request for information on first cousin marriages. The following day Reed was called to counsel "a family in which five of eight children had an heredomacular degeneration." From this beginning, he maintained a tally of thousands of counseling cases that he and the Dight Institute staff provided over a period of thirty-one years.

# **Genetic Counseling as Distinct from Eugenics**

From the start, Reed distinguished between the counseling he provided and the practice of eugenics by noting that the counseling was always voluntary and involved the consent of those receiving the service. He believed that "divorcing the two concepts of eugenics and genetic counseling contributed to the rapid growth of genetic counseling. Genetic counseling would have been rejected, in all probability, if it had been presented as a technique of eugenics." On the other hand, Reed did not disavow eugenics and traced the idea of genetic counseling directly back to Francis Galton,

<sup>&</sup>lt;sup>220</sup> Sheldon C. Reed, in Dight Institute *Bulletin no. 14*, (1974).

Molly Ladd-Taylor, "'A Kind of Genetic Social Work': Sheldon C. Reed and the Origins of Genetic Counseling," in *Women, Health, and Nation: Canada and the United States since 1945*, eds. Georgina Feldberg, Molly Ladd-Taylor, Alison Li, Kathryn McPherson (Montreal: McGill-Queens University Press, 2003), 67–84.

<sup>&</sup>lt;sup>222</sup> S. Reed, "A Short History of Genetic Counseling," in Dight Institute *Bulletin no. 14*, (1974).

the fountainhead from which modern genetic counseling developed. He was the first to study, in an adequate way, the contributions of heredity and environment in the development of human traits. . . No doubt he overemphasized the importance of heredity which reflected the attitudes of the Victorian era regarding race and class. His contribution to the lineage of genetic counseling resulted from his involvement in the eugenic movement from which genetic counseling evolved. <sup>223</sup>

Reed supported eugenic principles as long as genetic counseling was a voluntary, nondirected service for decision-making by individuals.<sup>224</sup>

Reed maintained a lifelong relationship with his advisor and mentor at Harvard University, William E. Castle, himself a student of Charles B. Davenport's (1866–1944). Castle signed one of his handwritten letters to Reed, "With love and best wishes, W. E. Castle, 'Uncle William' to you!" Reed was the last of Castle's many Ph.D. students who later became the backbone of academic genetics in the United States. The academic lineage of Davenport to Castle perhaps had a lasting effect on Reed. In 1903 Castle had experienced a passionate conversion to Mendelianism that he later conveyed to his students, including Reed, as an intense curiosity about the patterns of inherited characteristics but without much interest in the underlying biochemical mechanisms to explain them.<sup>226</sup>

<sup>&</sup>lt;sup>223</sup> S. Reed, "A Short History of Genetic Counseling," in Dight Institute *Bulletin no. 14*, (1974).

<sup>&</sup>lt;sup>224</sup> Molly Ladd-Taylor, "'A Kind of Genetic Social Work'," 67–84.

William E. Castle, handwritten letter to Sheldon Reed, undated, box 1, folder "Correspondence C," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>226</sup> See James Reed, "A Life in Experimental Biology," in *The Birth Control Movement and American Society: From Private Vice to Public Virtue* (Princeton, NJ: Princeton University Press, 1978), for a discussion about William E. Castle's career and its influence on his student Gregory Goodwin Pincus, the developer of the oral contraceptive, 317-33.

Reed's vision of genetic counseling differed significantly from that of his Danish colleague, Tage Kemp (1896–1964). <sup>227</sup> In 1929, Denmark passed a law allowing surgical sterilizations for genetic reasons and by 1942 about 2,000 individuals had been sterilized. Reed believed that the Danish operations "were voluntary from a legal point of view but in some cases it is quite conceivable that they represented a tradeoff between the person's basic attitudes and the gains obtained by freedom from further pregnancies, from future supervision and future troubles in general." Kemp's 1943 basic textbook of human genetics, Arveligheslaere (translated as "The Theory of Inheritance"), had a final chapter about "genetic-hygiene," meaning the provision of "advice and genetic prognosis." <sup>228</sup> Reed believed that Kemp's form of genetic counseling "was undoubtedly a eugenic tool," a conclusion he based on Kemp's seventeen case examples including "mental retardation, psychosis, convulsive seizures, muscular dystrophy, aniridia, deaf-mutism, ichthyosis vulgaris, and diabetes mellitus." The case studies all mentioned the options of "therapeutic abortion, sterilization or both," and to Reed represented "negative eugenics."229

Reed's work with pediatricians at the University of Minnesota expanded into what he eventually called "genetic counseling," a label that he took to the Dight Institute's advisory committee meeting on December 2, 1947 and that gained approval

Tage Kemp, *Arvelighedslaere*, (Copenhagen, DK: Ejnar Munksgaard, 1943). See http://icmm.ku.dk/klinikken/the\_clinic/history/tage\_kemp/ for a brief biography of Tage Kemp, accessed November 30, 2010. The University Institute of Human Genetics opened on October 14, 1938 in Copenhagen under Kemp's direction. His organization hosted the First International Congress of Human Genetics in 1956.

<sup>&</sup>lt;sup>228</sup> Translation courtesy of Frankie and Jole Shackelford.

<sup>&</sup>lt;sup>229</sup> Sheldon C. Reed, "A Short History of Genetic Counseling," in Dight Institute *Bulletin no. 14*, (1974).

because the members could not think of anything better.<sup>230</sup> Reed rejected the terms "genetic consultation" and "genetic advice" used by his predecessor, Clarence P. Oliver, as being insufficiently descriptive. He rejected the label "genetic hygiene" favored by Kemp as having unpleasant connotations for some Americans because hygiene conjures up images "of tooth pastes, deodorants, and other irrelevant items."

Historian Molly Ladd-Taylor has explored the "tangled relationship between eugenics and genetic counseling" as illustrated by Sheldon Reed's career. She found connections among Reed's "therapeutic orientation" and non-directive approach to genetic counseling for individuals and families, the "medicalization" of eugenics, and the pronatalist cultural atmosphere in post-World War II United States that aspired to happy families with healthy children. Ladd-Taylor concluded that Reed's position on genetic counseling reflected his core values of faith in science and the ability of "normal" people to make rational decisions about reproduction and genetic risk if they were fully informed.

Reed used the *eugenics* label when it was convenient and avoided it when not. He expressed a positive view of eugenics in his presidential address at the American Society of Human Genetics in 1956, recommending the establishment of local eugenics societies. Many of his publications in the 1960s used the word *eugenics* in a favorable way.<sup>233</sup> At

<sup>&</sup>lt;sup>230</sup> S. Reed, "A Short History of Genetic Counseling."

<sup>&</sup>lt;sup>231</sup> S. Reed, "A Short History of Genetic Counseling."

<sup>&</sup>lt;sup>232</sup> Molly Ladd-Taylor, "A Kind of Genetic Social Work", 67-84.

<sup>&</sup>lt;sup>233</sup> Sheldon C. Reed, "The Local Eugenics Society," *American Journal of Human Genetics* 9 (1957): 1–8; Sheldon C. Reed, "Toward a New Eugenics: The Importance of Differential Reproduction," *Eugenics Review* 57 (1965): 72–4.

the end of his career and after attitudes toward eugenics had shifted, Reed emphasized his reasoning for separating eugenics and genetic counseling,

The term 'genetic counseling' occurred to me as an appropriate description of the process which I thought of as a kind of genetic social work without eugenic connotations. I am still completely uncertain as to whether the net effect of genetic counseling is eugenic or dysgenic. It is my impression that my practice of divorcing the two concepts of eugenics and genetic counseling contributed to the rapid growth of genetic counseling. Genetic counseling would have been rejected, in all probability, if it had been presented as a technique of eugenics.<sup>234</sup>

Reed's frequently stated favorable view of eugenics throughout the 1950s and 1960s was replaced in later years by a more cautious attitude and vocabulary.

### Genetic Counseling at the University of Minnesota

Whereas Oliver had handled 53 cases of genetic counseling during his last year in Minnesota, Reed accomplished 81 in his first year and 135 the next. According to Reed, his genetic counseling differed from his predecessor's in that Oliver considered such consultations to be "more the basis for future studies than a simple effort to be of assistance to the family making the request." Oliver's concept of seeing families with genetic abnormalities at the request of medical doctors involved a research component, while Reed's was simply a medical service for individuals and families. During Reed's thirty-one-year tenure as director, he and the small staff at the Dight Institute provided more than 4,300 consultations to University of Minnesota physicians. They also responded through the mail to requests for genetic advice from individuals or their

<sup>&</sup>lt;sup>234</sup> Sheldon C. Reed, "A History of Genetic Counseling."

<sup>&</sup>lt;sup>235</sup> Sheldon C. Reed, Dight Institute *Bulletin no.* 6, (1949).

<sup>&</sup>lt;sup>236</sup> S. Reed, "A Short History of Genetic Counseling"

<sup>&</sup>lt;sup>237</sup> Ruth Schwartz Cowan, *Heredity and Hope: The Case for Genetic Screening* (Cambridge, MA: Harvard University Press, 2008), 223–45.

physicians outside the University of Minnesota and far beyond. Based upon these experiences, Reed developed the practice and theory of genetic counseling, the field of which he was the world-renowned founder.

Sheldon Reed wrote a series of three papers entitled, "Counseling in Human Genetics" in the first three Dight Institute *Bulletins* he produced (1949, 1951, 1953) and these formed the basis for his 1955 book, *Counseling in Medical Genetics*. <sup>238</sup> Reed considered that textbook one of his greatest achievements and commented frequently on the satisfaction he felt in spreading the science of human genetics widely through that means. <sup>239</sup> He changed the title from "human genetics" in the bulletins to "medical genetics" for the book to emphasize that physicians needed to assume the responsibility for genetic counseling in medical settings. <sup>240</sup> He put out new editions in 1963 and 1980.

# **Human Genetics Research at the Dight Institute**

Research in human genetics in the 1940s in the United States occurred in a variety of academic settings at major universities, sometimes in established zoology, biology, or specific genetics departments, sometimes in medical schools, and sometimes in separate programs such as the Dight Institute. Heredity clinics were established within some medical schools and were not necessarily connected with genetic research.<sup>241</sup> In 1955 Sheldon Reed listed thirteen existing heredity clinics existing in the United States.<sup>242</sup>

<sup>&</sup>lt;sup>238</sup>Sheldon C. Reed, *Counseling in Human Genetics* (Philadelphia, PA: W. B. Saunders Company, 1955).

<sup>&</sup>lt;sup>239</sup> S. Reed, "A Short History of Genetic Counseling."

 $<sup>^{240}</sup>$ S. Reed , "Counseling in Medical Genetics," iv.

<sup>&</sup>lt;sup>241</sup>Harper, A Short History, 277–82.

<sup>&</sup>lt;sup>242</sup>Harper, A Short History, 277–82.

Research at the Dight Institute started modestly with studies conducted by the directors and staff, usually in collaboration with others at the University of Minnesota, and focused on particular rare medical conditions. The published papers produced during Oliver's tenure as director mainly addressed the genetics of dental anomalies and was based on work with faculty in the School of Dentistry. Over time, the Dight Institute's research expanded in scope and complexity, aided by numerous post-graduate medical trainees and graduate students. Sheldon Reed guided research toward his interest in behavioral genetics which he noted also had the advantage of distinguishing the Dight Institute from the growing number of other human genetics programs in the United States. Accordingly, researchers at the Dight Institute paid particular attention to the inheritability of mental retardation and mental illness, conditions characterized by psychological and psychiatric disabilities that resulted in abnormal behavior.

Sheldon and Elizabeth Reed collaborated on a study that Sheldon considered the Dight Institute's greatest research achievement, the solution to "Cattell's paradox." Many previous studies had not found a correlation between larger family size and gradual decline in average IQ over generations as would be predicted. The Reeds and graduate student James Higgins found an explanation for this conundrum by analyzing the families of 549 inmates at the School for the Feeble-Minded in Faribault from 1911 to 1918 and more than 80,000 of their descendents. In the Reeds' study, they indeed found a correlation between large size of families and lower IQ when family members with no children were included in the analysis. The earlier studies had erroneously excluded

<sup>&</sup>lt;sup>243</sup> Elizabeth W. Reed and Sheldon C. Reed, *Mental Retardation: A Family Study* (Philadelphia, PA: W.B. Saunders, 1965).

childless family members from study.<sup>244</sup> Reed thought that these research findings explained why the eugenic fear of ever decreasing population IQ levels because of differential fertility rates failed to materialize even though "some mentally retarded persons reproduce luxuriantly while the mentally brilliant seldom produce large families."

In another massive study of a population of mentally defective individuals, Sheldon Reed collaborated with colleagues from the Warren State Hospital in Pennsylvania involving 99 patients with psychotic disorders and their offspring. <sup>246</sup> They found that psychotic individuals did not reproduce "at a rate high enough to replace themselves in the population, especially if they are institutionalized."

In one area of research, the Dight Institute's reputation has fared less well over time. J. Daniel Palm completed his Ph.D. at the Dight Institute in 1953.<sup>248</sup> Part of Palm's research included an analysis of descendents of two brothers who had settled in Minnesota, one with Huntington's disease and the other free of the disease. Palm and Reed published a paper that pointed out the far greater number of descendents of the affected brother (787) compared with the unaffected one (186) and concluded that

<sup>&</sup>lt;sup>244</sup>James V. Higgins, Elizabeth Reed, and Sheldon C. Reed, "Intelligence and Family Size: A Paradox Resolved," *Eugenics Quarterly* 9 (1962): 84–90.

<sup>&</sup>lt;sup>245</sup>Sheldon C. Reed, "Toward A New Eugenics."

<sup>&</sup>lt;sup>246</sup>Sheldon C. Reed, Carl Hartley, V. Elving Anderson, V. P. Phillips, and N. A. Johnson, *The Psychoses: Family Studies* (Philadelphia, PA: W. B. Saunders, 1973).

<sup>&</sup>lt;sup>247</sup> V. Elving Anderson, "Sheldon C. Reed."

<sup>&</sup>lt;sup>248</sup> J. Daniel Palm, "Detection of the Gene for Huntington's Chorea," (Ph.D. Dissertation, University of Minnesota, Minneapolis, 1953). Disclosure: J. Daniel Palm served as this author's faculty advisor in the Biology Department of St. Olaf College, Northfield, MN from 1965 to 1969.

Huntington's disease sufferers are more fecund than their unaffected siblings.<sup>249</sup> As historian Alice Wexler has pointed out, it was not until 1959 that "more responsible investigators," namely T. Edward Reed and James V. Neel, used the Huntington's registry in Michigan to reach the opposite conclusion. <sup>250</sup> Wexler cited the common misconception back to the time of George Huntington's first description of the disease that affected Huntington individuals have more descendents than unaffected siblings.<sup>251</sup> Reed's favorable orientation toward eugenic principles perhaps might have made him vulnerable to similar assumptions that had characterized the early eugenics movement. The conventional wisdom that people with Huntington's disease produced more children seemingly blinded Reed to the fallacy of depending on one family's reproductive history to draw a sweeping conclusion about population genetics. Curiously, he had corresponded quite recently with other geneticists about that exact point, for example, writing Bronson Price (1905–1978), a psychologist and behavioral geneticist working at the federal National Office of Vital Statistics, to inquire about the basis of Price's conclusion that differential birth rate statistics might be invalid because of "confounding of cause and effect." Reed stated, "While I suspect that you may be right in this statement, I am somewhat ignorant as to the evidence for it."252

<sup>&</sup>lt;sup>249</sup> Sheldon C. Reed and J. Daniel Palm, "Social Fitness Versus Reproductive Fitness," *Science* 113 (1951): 294–296.

<sup>&</sup>lt;sup>250</sup> T. E. Reed and James V. Neel, "Huntington's Chorea in Michigan: 2: Selection and Mutation," *American Journal of Human Genetics* 11 (1959): 107–136.

Alice Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease* (New Haven, CT: Yale University Press, 2008), 159–60.

<sup>&</sup>lt;sup>252</sup> Sheldon C. Reed to Bronson Price, March 17, 1949, folder "Correspondence R," Bronson Price Papers, American Philosophical Society.

### **Early Registries of Genetic Diseases**

James Neel visited the Reeds in Minneapolis on his way from Michigan to Japan in 1949. He toured the Dight Institute, reviewed its programs, shared information about disease registries, and exchanged opinions with Reed about population genetics. <sup>253</sup> In the era before the discovery of DNA, Neel and Reed agreed on the strategy of using genetic disease registries to estimate the frequency of abnormal genes in a defined population. Neel wrote Reed from Japan soon after leaving Minneapolis, "In view of the growing interests in mutation rates in man, I feel, as I indicated Saturday, that it would be well worth your while, now that you are this deeply into cysticfibrosis [sic] of the pancreas to nail that one down with a really good estimate of the incidence of the disease." Neel's experience with the Atomic Bomb Casualty Commission had heightened his awareness of population genetics and the possible results that ionizing radiation might have on human genes.

Registries for Huntington's disease at the universities in Minnesota and Michigan in the late 1940s and early 1950s represented some of the earliest applications of human genetics to population health. Sheldon Reed gave credit for the idea of a Huntington's disease registry in Minnesota to John S. Pearson, psychologist at the Rochester State Hospital and a Dight Institute research colleague. Pearson believed that the disease could

<sup>&</sup>lt;sup>253</sup> James V. Neel to Sheldon C. Reed, May 2, 1949; Sheldon C. Reed to James V. Neel, May 3, 1949, series 1, folder "Correspondence R," James V. Neel Papers, American Philosophical Society.

<sup>&</sup>lt;sup>254</sup> James V. Neel to Reed, May 11, 1949, series 1, folder "Correspondence R," James V. Neel Papers, American Philosophical Society.

<sup>&</sup>lt;sup>255</sup> M. Susan Lindee, Suffering Made Real: American Science and the Survivors at Hiroshima (Chicago, IL: University of Chicago Press, 1994).

be prevented or decreased with genetic counseling targeted to those families at risk. 256 He based his opinion partially on work done by Palm in educating a large Huntington's family in White Bear Lake about the inheritance of the disease and the risk of passing it to offspring. <sup>257</sup> Family members were relieved to understand their risk "even if it meant that a definite probability of developing the disease was substituted for a vague generalized fear." Although the family was Roman Catholic, the number of babies decreased significantly in the two years after Palm's education of the families. Pearson concluded that the family members were "spontaneously attempting a program of eugenic control even though they do not use artificial methods of birth control."258 Palm's experience coincided with Pearson's at the Rochester State Hospital where he found that among Huntington's patients "practically all of them understood for the first time how the heredity worked and what its consequences might be for their own families." Some took measures to insure that they "would not pass their gene for Huntington's chorea to any further descendents." <sup>259</sup> In 1953, Pearson proposed a statewide registry of Huntington's disease patients in Minnesota to reach everyone at risk with genetic counseling. He believed that the 585 cases in Minnesota could be traced to "no more than 23 individuals who have immigrated within the last 110 years."<sup>260</sup>

<sup>&</sup>lt;sup>256</sup> John S. Pearson to Sheldon C. Reed, December 3, 1953, box 1, folder "Correspondence P," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>257</sup> Palm, "Detection of the Gene."

<sup>&</sup>lt;sup>258</sup> John S. Pearson to Sheldon C. Reed, December 3, 1953, box 1, folder "Correspondence P," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>259</sup> Sheldon C. Reed to Helen G. Hammons, editor of *Eugenics Quarterly*, May 26, 1958, box 1, folder "Correspondence H," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>260</sup> John S. Pearson to Sheldon C. Reed. December 3, 1953.

James V. Neel at the University of Michigan started a Huntington's disease registry even earlier than the one in Minnesota. He and Estella Hughes, a medical social worker at Kalamazoo State Hospital, began a registry of Huntington families in southwestern Michigan in the late 1940s.<sup>261</sup> In 1948, Hughes contacted the Dight Institute to review copies of Huntington disease case studies she had sent to the Eugenics Record Office (ERO) before its records had been moved to Minnesota to be housed at the Dight Institute.<sup>262</sup> In early 1949 Hughes visited the Dight Institute in person to examine the reports of one of the Michigan Huntington's families.<sup>263</sup> She took some of the ERO records back to Michigan on loan, and Reed explicitly told her at that time that Palm was using some of her case reports in his study of differential fertility of affected and unaffected Huntington's individuals.<sup>264</sup> When Sheldon Reed traveled to Kalamazoo a few months later, he retrieved the borrowed ERO files so Palm could use them.<sup>265</sup> Hughes retired from Kalamazoo in 1953 and worked with Neel to expand their Huntington's

<sup>&</sup>lt;sup>261</sup> Estella Hughes, case study report, "Family History of Elizabeth Lucas, Patient at Kings Park State Hospital," August 9, 1917, series 1, box 37, folder "A:316," Eugenics Record Office Records, American Philosophical Society. In fulfillment of requirements to be an ERO field worker, Hughes interviewed the patient and her close relatives to analyze the family history of mental illness. Hughes was a graduate of West Michigan College of Education, had a master's degree in sociology from Kalamazoo College, and completed training as a psychiatric social worker at Smith College. Numerous pedigrees and case reports from Kalamazoo are contained in the ERO Records at the American Philosophical Society; Hughes to Reed September 5, 1952, box 1, folder "Correspondence H," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>262</sup> Estella Hughes to Sheldon C. Reed, December 6, 1948, box 1, folder "Correspondence H," Dight Institute Papers, University of Minnesota Archives. Hughes continued to submit case reports of Huntington's disease from Michigan to the Eugenics Record Office as long as it remained in operation.

<sup>&</sup>lt;sup>263</sup> Sheldon C. Reed to Estella Hughes, April 27, 1949, box 1, folder "Correspondence H," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>264</sup> Sheldon C. Reed to Estella Hughes, August 5, 1949, box 1, folder "Correspondence H," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>265</sup> Sheldon C. Reed to Estella Hughes, November 15, 1949, box 1, folder "Correspondence H," Dight Institute Papers, University of Minnesota Archives.

registry with cases from all ten of Michigan's state hospitals and the University of Michigan hospital.<sup>266</sup>

Hughes's observations about Huntington's families differed markedly from those of Palm and Pearson. Of the two hundred Huntington's families she had advised over more than thirty years, she encountered only eight individuals who took action to prevent the transmission of the disease through voluntary sterilization, two of them after having had several children and they themselves were in the early stages of the disease. Hughes held the opinion that physicians were woefully uninformed about Huntington's disease, and that they commonly missed the diagnosis and failed to counsel patients properly even when they identified the disease. Hughes told Reed that she kept a collection of "strange advice given" and "curious diagnoses on death certificates." <sup>267</sup>

In spite of the sustained contact between the groups in Michigan and Minnesota about Huntington's disease, misunderstanding arose about Palm's use of the Hughes ERO case reports. Neel complained to Reed in 1953 that Hughes had not known that Palm had included her cases in his study. Reed replied that he had told Hughes about Palm using her data five years earlier and she had not objected. Palm had acknowledged

<sup>&</sup>lt;sup>266</sup> Estella Hughes to Sheldon C. Reed, undated, box 1, folder "Correspondence H," Dight Institute Papers, University of Minnesota Archives. The Atomic Energy Commission funded the Huntington's disease study at the University of Michigan.

<sup>&</sup>lt;sup>267</sup> Estella Hughes to Sheldon C. Reed, September 5, 1952, box 1, folder "Correspondence H," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>268</sup> James V. Neel to Sheldon C. Reed, October 26, 1953, series 1, folder "Correspondence R-Ri," James V. Neel Papers, American Philosophical Society.

Hughes as the originator of the case reports in his thesis, and Reed said he considered the material in the ERO files in Minneapolis to be at the disposal of the Dight Institute.<sup>269</sup>

# **Reed's Connections with Other Human Geneticists**

Reed cultivated an extensive network of colleagues in human genetics, exchanging ideas about projects, discussing data from studies, reviewing scientific papers, and planning events and conferences. His personal contacts in the United States and in other countries grew to hundreds of people with whom he maintained correspondence, visits, and friendships. Reed mentored numerous graduate students and medical residents and he hosted researchers from other universities in the United States and abroad. For example, Jan A. Böök, spent one year at the Dight Institute on a United States Public Health Service fellowship in 1949–1950. He returned to Sweden to be the assistant director of the State Institute for Human Genetics at Uppsala. 270 He and Reed published a paper together that used some of Böök's research in an isolated defined Swedish population of 8,651 people to determine a frequency rate for mongolism, another illustration of Reed's interest in population genetics. <sup>271</sup> Reed worked with University of Minnesota psychologists and psychiatrists to obtain federal training grants for research in behavioral genetics that lead to more than 60 Ph.D.s being awarded to students affiliated with the Dight Institute.<sup>272</sup> Another example of Reed mentoring a fellow human geneticist was Gordon Allen, never actually one of Reed's students, who

<sup>&</sup>lt;sup>269</sup> Sheldon C. Reed to James V. Neel, October 29, 1953, box 1, folder "Correspondence N." Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>270</sup> Sheldon Reed, Dight Institute *Bulletin No.* 7, (1951).

<sup>&</sup>lt;sup>271</sup> Jan A. Böök and Sheldon C. Reed, "Empiric Risk Figures in Mongolism," *Journal of the American Medical Association* 143 (1950): 730–2.

<sup>&</sup>lt;sup>272</sup> Anderson, "Sheldon Reed."

met Reed only because Allen had applied to the University of Minnesota Medical School. Reed and Allen, who became a physician and leader in human genetics at the National Institutes of Mental Health, maintained contact for decades. Allen periodically wrote to Reed seeking advice about his experiences in medical school and asking for help with the decisions about what specialty to pursue and how to launch his career.<sup>273</sup>

Reed participated in the national professional organizations for geneticists and was a founding member of the American Society of Human Genetics (ASHG) when it organized in 1948 as a field separate from general genetics. He hosted the organization's annual meeting in Minneapolis in 1951 and served as its president in 1956. In an interview in 1973, Reed recalled that in 1948 the human geneticists almost unanimously had agreed that they got short shrift at the annual meetings of the Genetics Society of America and needed their own professional society. The new ASHG had only 50 members at the beginning, many of them New York physicians pressured to join by Franz Kallmann who worked on psychiatric genetics at the New York Psychiatric Institute. H. J. Muller, the first president, was "involved as figurehead," according to

<sup>&</sup>lt;sup>273</sup> Letters, Gordon Allen and Sheldon C. Reed, box 1, folder "Correspondence A," Dight Institute Papers, University of Minnesota Archives,

Herlof H. Strandskov, handwritten scrapbook, "Account of First Annual Meeting, Washington, DC, September 11, 1948 of the American Society for Human Genetics," series VII, Papers of the American Society of Human Genetics, American Philosophical Society.

<sup>&</sup>lt;sup>275</sup> Handwritten note, author unknown, listing the sites of the annual meetings of the American Society of Human Genetics, 1948–1967, series V, folder, "Annual meetings 1959–69," Papers of the American Society of Human Genetics, American Philosophical Society.

<sup>&</sup>lt;sup>276</sup> Arno Motulsky, copy of typewritten transcript of interview with Sheldon C. Reed, 1979, box 1, folder "Correspondence M," Dight Institute Papers, University of Minnesota Archives.

European Archives of Psychiatry and Clinical Neuroscience 229 (1981): 273–76.

Reed.<sup>278</sup> In regard to the timing and as a possible reaction to Nazi eugenics, Reed felt that, "It was certainly on everybody's mind and it was determined that this would be a purely human genetics scientific society that would have nothing to do with social issues."<sup>279</sup>

Extensive professional and personal correspondence between Reed and James V. Neel at the University of Michigan attest to their lifelong professional and personal connections. Although Neel perhaps exceeded Reed in intellectual achievements and scientific output and was considered by many people to be the founder of the field of human genetics, he and Reed continued to support each other in a variety of ways during their parallel careers. Their relationship had aspects of collaboration but it was also characterized by an uneasy rivalry, perhaps because they realized the newness of their field and their historic roles in shaping a new field of knowledge. They had few peers in the 1940s and early 1950s that rivaled their achievements in terms of scientific productivity, a broad vision for their emerging field, leadership of new models for institutional human genetics programs, and the promotion of population genetics.

Curt Stern at the University of Rochester, where Neel trained in medicine and in genetics, provided Neel with a formidable role model and mentor.<sup>281</sup> Neel eulogized Stern as the last geneticist to master the entire field of genetics before it got too large for one person to manage. Neel practiced clinical medicine alongside distinguished career as

<sup>&</sup>lt;sup>278</sup> Motulsky interview of Sheldon C. Reed.

<sup>&</sup>lt;sup>279</sup> Motulsky interview of Sheldon C. Reed.

<sup>&</sup>lt;sup>280</sup> Sheldon C. Reed to James V. Neel, October 21, 1948, and Neel to Reed, November 12, 1948, folder "Correspondence R," James V. Neel Papers, American Philosophical Society.

<sup>&</sup>lt;sup>281</sup> James V. Neel, "Curt Stern, 1902–1981," in *Annual Review of Genetics 1983*, eds. H.L. Roman, Allan Campbell, Laurence Sandler, *Annual Reviews*. 17 (1984): 1–10.

a human geneticist and was a trailblazer in almost every aspect of human genetics: investigator of specific errors of metabolism and other genetic diseases; founder and head of the University of Michigan's Heredity Clinic, director of the United States Atomic Bomb Casualty Commission; researcher into the reproductive patterns of remote and isolated pre-contact Amazonian aboriginal tribes; student of theoretical population genetics; and as his autobiography labeled himself, "physician to the gene pool." Neel believed that "the advent of the atomic age stimulated the development of human genetics. The potential genetic effects in increased exposure to radiation were very much on both the scientific and lay minds from the moment of the detonation of the atomic bombs." The events in Japan had given the issue of radiation damage to genetic material, first described by H.J. Muller in 1927, "a certain immediacy."

Both Neel and Reed were concerned about their legacies in human genetics. The correspondence between the two men about who was first revealed their personalities, Neel's assertive and competitive and Reed's careful and diplomatic. For example, in 1974 Neel wrote to Reed to inquire about the date of the first genetic counseling at Minnesota. His entire letter read,

I am stuck with a little article on the history of human genetics in this country. It looks as if Minnesota and Michigan were the first two

<sup>&</sup>lt;sup>282</sup> James V. Neel, *Physician to the Gene Pool: Genetic Lessons and Other Stories* (New York, NY: J. Wiley & Sons, 1994).

<sup>&</sup>lt;sup>283</sup> For an analysis of policy decisions of the ABCC, see M. Susan Lindee, "Atonement: Understanding the No-Treatment Policy of the Atomic Bomb Casualty Commission," *Bulletin of the History of Medicine* 68 (1994): 454–90. Also, M. Susan Lindee, *Suffering Made Real*.

<sup>&</sup>lt;sup>284</sup> James V. Neel to Kenneth Ludmerer, November 2, 1970, series 1, folder "Correspondence Lo-Mac," James V. Neel Papers, American Philosophical Society.

<sup>&</sup>lt;sup>285</sup> Verified in a personal telephone communication with Lee E. Schacht, January 3, 2009.

institutions to offer genetic counseling. We began in 1941. What was the official date when you undertook such responsibilities?

Reed answered with a handwritten note across the bottom of Neel's original letter,

I did my first counseling case (here) on Aug. 18, 1947. However, Pete Oliver had been doing 'genetic advising' here with his first 'formal' case on November 13, 1941 and he did 232 cases before I came. Larry Snyder and Madge Macklin had been doing advising several years before that. The only thing I did first was to coin the term 'genetic counseling' for better or worse."<sup>286</sup>

Reed also reminded Neel that he had written the first textbook on the subject, *Counseling* in *Medical Genetics*, in 1955.<sup>287</sup>

### Reed's Involvement in International Networks of Human Geneticists

During the formative years of human genetics, Reed and other founders of the field had to contend with the reviled legacy of the events that had occurred in Nazi Germany in the guise of eugenics. Reed had met many of the top German human geneticists in September 1932 when he attended the 6<sup>th</sup> International Congress of Genetics at Ithaca, NY.<sup>288</sup> In 1939 Reed toured Scandinavia, crossed through Nazi Germany without stopping, visited Paris and London, then attended the 7<sup>th</sup> International Congress on Genetics in London, Cambridge, and Edinburgh August 15–30, 1939. That Congress ended with the abrupt departure of the German and Italian scientists a few days before the start of the Second World War.<sup>289</sup>

<sup>&</sup>lt;sup>286</sup> James V. Neel to Sheldon C. Reed, November 21, 1974, series 1, folder "Correspondence R," James V. Neel Papers, American Philosophical Society.

<sup>&</sup>lt;sup>287</sup> S. Reed, Counseling in Medical Genetics.

<sup>&</sup>lt;sup>288</sup> Motulsky interview of Sheldon C. Reed.

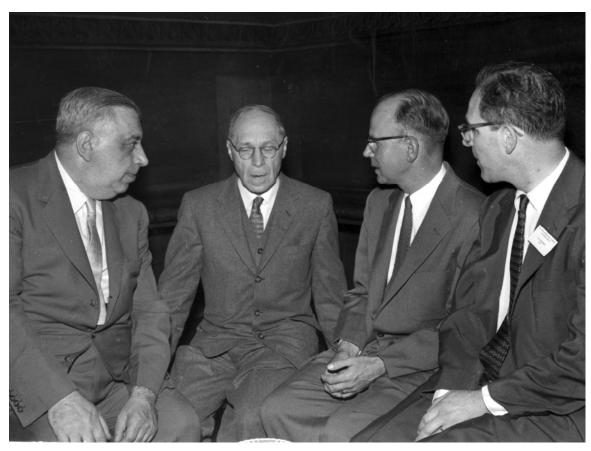
<sup>&</sup>lt;sup>289</sup> Motulsky interview of Sheldon C. Reed.

Reed maintained an extensive international network and exerted influence as a human geneticist globally. While directing the Dight Institute, he traveled abroad several times, first to visit programs in Denmark and Sweden to obtain ideas for developing the Dight Institute and later to attend the First International Congress on Human Genetics hosted by Tage Kemp in Denmark in August 1956 where Reed presented a talk about genetic counseling. Photograms are also as a conference included talks by Elizabeth Reed about her research on the genetics of mental retardation and by Lee E. Schacht of the Minnesota Department of Health, the first human geneticist employed by a state department of health in the United States, about public health genetics units. These presentations at international congresses show the degree to which work in Minnesota on human genetics had gained international attention.

 $<sup>^{290}</sup>$  V. Elving Anderson, "Sheldon Reed." 630.

<sup>&</sup>lt;sup>291</sup> Sheldon Reed, in Dight Institute *Bulletin No. 10*, (1957).

<sup>&</sup>lt;sup>292</sup> Lee E. Schacht, copy of typewritten resume, provided to the author.



*Figure 6.* American Geneticists aboard the M.S. *Bergensfjord* en route to the 1st International Congress of Human Genetics in Copenhagen (Franz J. Kallmann, Hermann J. Muller, Sheldon C. Reed, Arthur G. Steinberg, 1956. (University of Minnesota Archives)

# **Genetic Counseling and the Catholic Church**

High-ranking officials of the Roman Catholic Church viewed Reed's work in genetic counseling favorably. In 1958, Pope Pius XII mentioned his book on medical genetics in two discourses presented in Rome at international congresses on hematology. The Pope recommended that genetic counseling centers patterned after the Dight Institute be developed everywhere in the world. Citing the example of

<sup>&</sup>lt;sup>293</sup> Pope Pius XII, English translations of "Discourse of His Holiness Pope Pius XII to the Members of the International Congress on Blood Transfusion, September 5, 1958, and to the Seventh International Congress of Hematology, September 12, 1958," in Dight Institute *Bulletin* No. 11, (1961).

thalassemia major (Cooley's anemia) that was so prevalent in Italy, the Pope recommended genetic counseling, saying,

For this purpose, there could be organized, after the manner of the American "Dight Institute", [sic] service centers of information and consultation, which engaged and married couples could consult with full confidence on questions of heredity, in order to have greater assurance of happiness and security in their union. These centers would not only give information, it would help the interested persons to apply efficacious remedies. In a work which, we have been assured, is authoritative in this matter (Sheldon C. Reed, Counseling in Medical Genetics), We have read that the chief purpose of the consultation is to make the interested persons understand the problems of genetics which appear in their families.<sup>294</sup>

The Pope's discourse cited the benefit of genetic counseling in preventing the parents from blaming each other for genetically abnormal children. According to the Pope, genetic counseling was "eugenic" if prospective parents decided not to have more children when the risk of genetic disease was high or if they accepted more children when the risk was low. The Pope concluded that couples were likely to have more children than they might have had without genetic counseling and noted that genetic consultation reflected "religious principles" by leaving the decision to have more children up to the parents after they are informed of true risks. "The Dight Institute is therefore not a clinic meant to restrain fecundity; information is not furnished there on the way of 'planning' families, since that question does not fall within its scope."

Encouraged by these remarks, Reed communicated with the Vatican about approving birth control to avoid producing children with severe, disabling genetic diseases. In a letter to His Holiness, Pope Paul VI, in 1965, Reed urged the Pope to

<sup>&</sup>lt;sup>294</sup> Pope Pius XII, "Discourse."

<sup>&</sup>lt;sup>295</sup> Pope Pius XII, "Discourse."

authorize birth control "for parents with risk of genetic disease." <sup>296</sup> After mentioning offhand that Mendel had been a Roman Catholic priest, Reed urged that "that the Holy See may come to accept some of the medical methods now available in order that responsible parenthood may be a joy rather than a life of frustration and distress." Reed's recommendation was not rejected immediately as attested by communication he received from Father John A. O'Brien of Notre Dame University to whom Reed's letter had been forwarded from Rome. Labeled "Confidential," O'Brien's letter stated, "You will be glad to learn that there has been significant theological development in the Church re the use of progestin pills under certain circumstances."<sup>297</sup> O'Brien cited "what theologians call a 'solidly probable opinion' which would enable pastors to sanction the use of the progestin pills in the circumstances mentioned in your letter, even though the Church has not officially made such a public pronouncement as yet." He disclosed that "the opinion just mentioned was widely and almost universally held," at a closed conference of thirty leading moralists attending a conference at Notre Dame. Their recommendation that the birth control pill be allowed for preventing genetic diseases apparently was not eventually accepted in Rome.

# Reed's Retirement and the End of the Dight Institute

Sheldon Reed became Emeritus Director of the Dight Institute on July 1, 1978, marking exactly thirty-one years of service. In retirement, besides continuing his hobby of breeding African violets, he helped his church sponsor a Hmong refugee family and

<sup>&</sup>lt;sup>296</sup> Sheldon Reed to His Holiness, Pope Paul VI, April 28, 1965, box 1, folder "Correspondence O, 1947-1981," Dight Institute Papers, University of Minnesota Archives.

John A. O'Brien to Sheldon Reed, May 5, 1965, box 1, folder "Correspondence O, 1947-1981," Dight Institute Papers, University of Minnesota Archives.

learned to speak the Hmong language that is so difficult that only a small number of non-Hmong Minnesotans have ever succeeded in mastering it. Reed spoke it well enough to teach young people how to read their own language and give them mathematics tutorials in Hmong.<sup>298</sup>

Reed's ambivalence and nervousness about eugenics at the end of his career came out strongly in a newspaper interview in 1983 about a person in Minneapolis dedicated to studying the connections between eugenics, psychiatry, and Nazi genocide. Reporter Patricia Ohmans asked Reed about Charles Dight's correspondence with Nazi officials in the early 1930s and what that meant for his legacy at the Dight Institute for Human Genetics. Reed expressed surprise that Dight had corresponded with Hitler and declared, "Today the Dight Institute has nothing of worth for the person interested in eugenics." He professed disinterest in Dight, claiming, "I'm not all that intrigued by historical things, I'm more interested in the future." He conceded that although eugenics was "given a bad name after the war," the Dight Institute's research "has never been anything which we have called eugenics. Human genetics is the study of genes and people. Eugenics is the attempt to use genetics for political purposes." In the next breath, Reed defended the basic goal of eugenics, the improvement of human heredity, stating that, 'Geneticists realized that the concept behind eugenics was good, but the program was too

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<sup>&</sup>lt;sup>298</sup> V. Elving Anderson, "Sheldon C. Reed, Ph.D., (November 7, 1910–February 1, 2003): Genetic Counseling, Behavioral Genetics," *American Journal of Human Genetics* 73 (2003): 1-4.

complicated. The concept is still fine, but we still don't know how to eliminate genes in any sensible fashion."<sup>299</sup>

Sheldon Reed retired in time to avoid the intense barrage of university politics that resulted from his retirement and the lack of a strong, willing internal candidate to succeed him. The field of human genetics was rapidly shifting to molecular genetics and the medicalization of genetic conditions. The uncertainty of leadership at the Dight Institute and changing genetic concepts led to stormy debates about where genetics belonged organizationally at the University of Minnesota. Reed, in fact, had stayed on an extra six months while university committees studied the future of genetics and the Dight Institute. The investigations included eight extensive meetings and fourteen formal interviews with high-ranking faculty members in the College of Biological Science, the Medical School and the School of Dentistry. The committees could only agree to further "examine the future and present role of the Dight Institute and the kind of leadership that will be needed in the years ahead." In those years that followed Reed's departure, the Dight Institute could not fend off criticism that it was insufficiently attuned to the new and powerful technology of molecular genetics and had no plan to provide real leadership in a molecular-based, medical application of genetics that the leaders in the Medical School wanted. Some faculty members such as Dennis W. Wilson, Head of the College of Biological Science Microbiology Department, offered support but no hope for a

<sup>&</sup>lt;sup>299</sup> Patricia Ohmans, "What If He's Right? En Route to a Theory of Psychiatry's Racist Roots, a Parking Lot Attendant Uncovers the Sour Truth Behind the University's Dight Institute for Human Genetics," *Minneapolis City Pages*, July 20, 1983, 7–11, 14.

<sup>&</sup>lt;sup>300</sup> T. J. Bouchard, F. Forro, B. L. Shapiro, R. L. Vernier, memorandum to Deans Caldecott, Gault, and Ibele, August 18, 1977, box 2, folder "Future of Dight Institute 1974-1984," Dight Institute Papers, University of Minnesota Archives.

proposal for an independent Interdisciplinary Program in Human Genetics offered by the Dight Institute's acting director, Elving Anderson, stating,

No doubt, Elving, it is a scholarly, logical and well-thought-out proposal. Unfortunately, until the political realities are resolved between the Medical School and the College of Biological Sciences, no proposal from the Dight Institute will ever get off the ground."<sup>301</sup>

Discussions continued for such a long time that former allies of the Dight Institute in the Medical School, such as Richard King, lost patience and, in 1983, refused further support. King captured the tone and substance of the debate:

Over the past few years I have supported the Dight Institute as a focus for human genetics. I no longer support this position. The Dight Institute, the Department of Genetics and Cell Biology, and the College of Biological Sciences have had 5 years and more to develop a program in human genetics and they have failed. No program exists and there is no real hope that a program will exist in the near future. We can wait no longer. Frustration with the lack of a genetics program is widespread among the medical school faculty. No further discussion is necessary. Because of this, I must also resign from the Dight committee. I remove my support for the latest proposal. The focus for the development of human genetics must be in the Health Sciences, where the faculty and the administration will encourage and support this effort, and I will apply myself to this goal. 302

Seven medical school department heads signed an open letter to the Vice President for Health Services in the new Academic Health Center proposing to end the Dight's existence by transferring it into the Medical School and dropping the Dight name. 303 Anderson, who had served as interim director of the Dight Institute after Reed's retirement until the appointment of Jack Sheppard as director of the Dight Institute in

<sup>&</sup>lt;sup>301</sup> Dennis Watson to Elving Anderson, March 22, 1983, box 2, folder "Administrative 1980–1988," Dight Institute Papers, University of Minnesota Archives.

<sup>302</sup> Richard King to V. Elving Anderson, March 17, 1983, box 2, folder "Administrative 1980–1988," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>303</sup> Open Letter to Neal Vancelow from seven medical school department heads, April 11, 1983, box 2, folder "Administrative 1980–1988," Dight Institute Papers, University of Minnesota Archives.

1982, fought to preserve the program as the Dight Institute for Human Behavioral Genetics within the College of Biological Science but to no avail. He and Sheppard had a few defenders such as Burton L. Shapiro in the School of Dentistry, a long-time supporter of the Dight Institute who raised arguments against defining human genetics entirely as a medical molecular biological enterprise.

In recent days, I have become aware that there are thoughts about subsuming the educational, research, and clinical enterprise of human genetics and medical genetics under the rubric of molecular genetics. It wasn't until yesterday that it became clear to me . . . that clinical as well as educational human genetics activities would be considered to be under the umbrella of molecular genetics. Molecular biological technology is enormously powerful. The analytical powers are like a laser beam in comparison with previous methods. But to forsake a discipline to a technology is a serious step. . . To replace a discipline with a technology is to give up tradition, discipline, fundamental questions, and, most crushing of all, perspective. . . A reasoned approach would be the inclusion and strong support of molecular genetics in the context of human genetics—not the converse. <sup>305</sup>

In 1988, the Dight Institute for Human Genetics ceased to exist as an entity within the College of Biological Science and became part of the medical school as the Institute of Human Genetics.

Until technology changed human genetic research and practice in the 1970s, the Dight Institute was in the vanguard of academic human genetics education, research, and service programs in the United States. Before its decline, it possessed the capacity to shape public policy about genetics and position human genetics to benefit Minnesota's population. The next step toward that goal was to apply the science of human genetics to

<sup>&</sup>lt;sup>304</sup> V. Elving Anderson to Richard Caldecott November 17, 1983, box 2, folder "Administrative 1980–1988," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>305</sup> Burton L. Shapiro to Ken Keller and Neal Vanselow, March 2, 1984, box 2, folder "Future of Dight Institute 1974–1984," Dight Institute Papers, University of Minnesota Archives.

populations as public health genetic policy. But, before that could happen, it was necessary for Sheldon Reed and the Dight Institute to reach out to the citizens of Minnesota, primarily through its affiliated advocacy group, the Minnesota Human Genetics League, to foster the social capital to make political change in the form of laws that established genetics as a public responsibility and public health enterprise.

#### **CHAPTER 4**

# The Social Dimensions of Heredity: The Minnesota Human Genetics League, Public Relations, and Political Activism

Whereas, the threat of adverse effect of atomic radiation upon the heredity of a population making vitally necessary the gathering and compilation of additional knowledge in this field;

Now, therefore, it is hereby declared that the establishment of a program for the promotion of the science of genetics is a matter of state concern and necessity in planning for public health and welfare.<sup>306</sup>

-Minnesota Law, 1959.

Despite the negative legacies of the eugenics movement in the United States and the Nazi racial policies, the field of human genetics grew after World War II.

Countervailing forces worked to favor the growth and acceptance of human genetics in academia and within the greater society. Knowledge in the field of human genetics advanced rapidly, transforming it from "a medical backwater" in the 1950s to a critical component of medicine and public health in the 1960s. <sup>307</sup> Genetic counseling and prenatal diagnosis changed the way that people perceived human genetics. <sup>308</sup> Physicians could diagnose genetic diseases before birth through amniocentesis starting in the 1950s. <sup>309</sup> Birth control and abortion became legal. In many people's view, "the

 $<sup>^{306}</sup>$  Chapter 572 of Minnesota Session Laws, Signed by Governor Orville Freeman on April 24, 1959, reprinted in the Dight Institute *Bulletin no. 11*, (1959).

 $<sup>^{307}</sup>$  M. Susan Lindee, *Moments of Truth in Genetic Medicine* (Baltimore: The Johns Hopkins Press, 2005), 1.

<sup>&</sup>lt;sup>308</sup> Ruth Schwartz Cowan, *Heredity and Hope: The Case for Genetic Screening* (Boston, MA: Harvard University Press, 2008), 71-116.

<sup>&</sup>lt;sup>309</sup> Lindee, *Moments of Truth*, 14.

combination of amniocentesis, prenatal diagnosis, and selective abortion would make possible new, more acceptable and legitimate forms of eugenics."<sup>310</sup>

On the societal level, fear of radiation in the atmosphere reached near-panic proportions in the 1950s and awareness grew that radiation posed a genetic risk of mutations. Also during that decade and into the 1960s many people became aware of the hazards of environmental pollution and potential harm to human genes.<sup>311</sup> In addition, people in the post-war era began to be concerned about global overpopulation, and some wondered what effect "the population bomb" would have on the human gene pool.<sup>312</sup> Consequently, issues concerning human genetics raised complicated legal and political questions above the level of the individual. Genetics seemed to have potential for offering benefits both to the genetic health of individuals and to society.

The first human geneticists such as Sheldon Reed enthusiastically assumed responsibility for promoting their field's possible contributions to people and society. Reed understood that human genetics needed sound science to escape from venturing into further disastrous public policies such as the former eugenics movement and that it also required massive amounts of persuasion and education before genetics would be accepted as an application of medicine and public health. To that end, he tirelessly promoted human genetics from his base at the Dight Institute for Human Genetics and used every technique he thought might work—writing for the mass media, producing textbooks, and

<sup>310</sup> Lindee, Moments of Truth, 15–16.

<sup>&</sup>lt;sup>311</sup> Rachel Carson, Silent Spring (New York, NY: Ballantine Books, 1963).

<sup>&</sup>lt;sup>312</sup> Paul R. Ehrlich, *The Population Bomb* (London, UK: Hamish and Hamilton, 1968); James V. Neel, "Changing Patterns of Disease and Their Implications for Vital Statistics and Genetics," in *Proceedings of the Sponsored by the United Nations and the World Health Organization on the Use of Vital and Health Statistics for Genetic and Radiation Studies, Geneva 5–9 September 1960, (New York, NY: United Nations, 1962).* 

lecturing to large public audiences. Like Charles Dight, Reed appreciated the power of the mass media, especially newspapers and magazines, to influence public opinion and policy. He touted a two-part feature article about the Dight Institute in the *Minneapolis Sunday Tribune* (July 31 and August 7, 1949) that garnered more than a hundred letters of inquiry about genetic counseling. Short descriptions of the Dight Institute in *Your Life* (April 1950) and *Coronet* (April 1951) resulted in several hundred inquiries about genetic information or counseling.<sup>313</sup>

#### The Need to Reframe Eugenics in Dight's Will

Charles Dight required the University of Minnesota to disseminate knowledge about human genetics beyond the Dight Institute in two ways. First, he stipulated that information about human genetics would be spread by means of popular and widely read publications accessible to everyone. Second, he specified that the University of Minnesota would "form eugenic societies" to promote the benefits of human genetics. <sup>314</sup> The leaders of the Dight Institute, first Clarence Oliver and later Sheldon Reed, knew that Dight's eugenics organization, the Minnesota Eugenics Society, had failed to generate broad social support, and they took steps to avoid having their efforts suffer the same lack of public acceptance. Dight's second stipulation, to form eugenic societies, raised difficult questions, the first of which was to understand why the eugenics movement in Minnesota and elsewhere had failed to achieve broad respectability and acceptance.

<sup>&</sup>lt;sup>313</sup> Sheldon C. Reed, in Dight Institute *Bulletin no.* 7, (1951).

<sup>314</sup> Charles F. Dight, Last Will and Testament (copy), March 1, 1927, box 2, folder "Dight, Charles Freemont, Will," Dight Institute Papers, University of Minnesota Archives."

Reed believed that the eugenics movement in Minnesota had collapsed so suddenly in the early 1930s because most people had not perceived eugenics as urgent or effective in improving human heredity. He also ascribed the failure of Minnesota's eugenics movement to the lack of socially prominent and politically influential supporters, in his words, "social power," and to the lack of logistical support, staff, and money to keep the movement running properly. In Reed's opinion, the failure of the Minnesota Eugenics Society had "merely meant that a preliminary experiment, for which there had been no model, was completed. A decade later the spirit was to rise again from Dr. Dight's remains, and the Society was to be resurrected. That new eugenics society consisted of the Minnesota Human Genetics League (MHGL), an organization that Reed believed completely fulfilled Charles Dight's mandate for the university to establish an effective eugenics society:

There can be no doubt that if Dr. Dight could return today he would be elated at the growth, stability and progress made by the League under the guidance of Dr. Minnich. He would realize that his investment had paid high dividends. Indeed, as none of the financial return from the Dight trust is utilized directly by the League, the canny old doctor is coming as close to getting something for nothing as anyone could.<sup>317</sup>

Established as an independent organization in 1945, the Minnesota Human Genetics

League served as Minnesota's public champion for human heredity, as a support group

for the Dight Institute of Human Genetics, and as a repository of the "social power"

needed to change society.

<sup>315</sup> Dight's will.

<sup>316</sup> Dight's will.

<sup>&</sup>lt;sup>317</sup> Sheldon C. Reed, "The Minnesota Human Genetics League, Part 5 of 6," *Minnesota Medicine* 40 (1957): 183.

On the national level, Frederick Osborn (1889–1981), president of the American Eugenics Society from 1946 to 1952, speculated on reasons his organization had barely survived extinction after the World War II. By 1931, according to Osborn, the luster had worn off the eugenics movement. The early eugenicists, he noted, had placed "a false and distasteful emphasis on race and social class" that had destroyed their credibility. Furthermore, eugenics was not actually a scientific field but a collection of ideas that crossed traditional disciplines such as sociology and biology and thereby created confusion about its boundaries during a time of academic specialization. Although not a factor until 1932, Osborn noted that eugenics could not overcome the intense public aversion to the atrocities that the Nazi regime had committed under the guise of eugenics. His last reason for the demise of eugenics was that the powerful American social value of individualism prevented many people from accepting the idea that different individuals "are born with different genetic potentials, with different possibilities for defects, for happiness, or for service to the community."

Osborn's analysis for the collapse of eugenics in the 1930s did not include an even likelier reason, namely, that the science supporting eugenics prior to the development of the field of human genetics in the 1940s had not been sufficient to justify and support its strategies.<sup>319</sup> Between the 1930s and 1950s, the scope and quality of human genetic science went from rudimentary to fully developed. As a consequence, during the science's rudimentary stage, the eugenics movement had established only a

<sup>&</sup>lt;sup>318</sup> Frederick Osborn, typewritten and edited manuscript, "The Organizational History of the American Eugenics Society," January 20, 1971, folder "Osborn, Frederick, History of AES," American Eugenic Society Records, American Philosophical Society.

<sup>&</sup>lt;sup>319</sup> Peter S. Harper, *A Short History of Medical Genetics* (New York, NY: Oxford University Press, 2008), 234–66.

few, tenuous connections with faculty and staff at the University of Minnesota. The field of human genetics after World War II, as demonstrated by the experience of the Dight Institute, based on science, enjoyed a solid academic home and was integrated into the rest of the university.

Reed held a positive opinion of Charles Dight. He thought that Dight had been "a man intellectually in advance of his times" who was able to maintain faith in something new even when others doubted. Reed listed as evidence Dight's experiment with prepaid medical insurance in the early twentieth century, his crusade for mandatory pasteurization of milk during the World War I, and his support for the "voluntary sterilization of the unfit, and for the fit whose genetics indicate a serious likelihood of the production of further abnormal children." Reed took these examples as evidence of Dight's orientation towards a public health approach in solving society's problems. <sup>320</sup> He admired Dight's tenacity in promoting public health goals, noting that, "The opponents of voluntary sterilization are more strongly entrenched than were the milk companies that opposed pasteurization, but no group can hold back permanently the benefits medicine can bestow." <sup>321</sup>

# The Minnesota Human Genetics League

The University of Minnesota addressed Dight's stipulation "to establish eugenics societies" later than the other directives of his will. Clarence Oliver waited three years

<sup>&</sup>lt;sup>320</sup> For a discussion of the drive to provide a safe milk supply in Minnesota, see Philip D. Jordan, *The People's Health: A History of Public Health in Minnesota to 1948* (St. Paul. MN: Minnesota Historical Society, 1953), 162–75.

<sup>&</sup>lt;sup>321</sup> Sheldon C. Reed, "The Minnesota Eugenics Society, Part 3 of a Series," *Minnesota Medicine* 40 (1957): 50.

before establishing a subgroup of the Dight Institute's advisory committee to consider the eugenics society provision in the will. After study, the subcommittee concluded that eugenic strategies that promoted "legislation regulating the reproduction of the public were not likely to be successful until more knowledge about human genetics made such measures justified." They recommended instead that the Dight Institute form a legally independent organization to support the acquisition and dissemination of knowledge about "human genetics, eugenics, and population problems." 322

The Dight Institute's advisory committee accepted the subcommittee report and decided to call the new organization the Minnesota Human Genetics League. It was incorporated in October 1945 as a legally entity separate from the Dight Institute. The first officers of the Minnesota Human Genetics League were comprised of stalwart supporters and founders of the Dight Institute: Zoology Professor and Department Chair, Dwight E. Minnich, President; Graduate School Dean Theodore C. Blegen, Treasurer; and Dight Institute Director. Clarence P. Oliver, Secretary.

The leaders of the new organization were determined to avoid the lack of societal support and power that had plagued the Minnesota Eugenics Society. They made sure that, "This time there was to be no lack of participation by prominent citizens generally to be found working for all good causes." Using his connections with leaders in the birth control movement in Minnesota, Minnich recruited influential citizens who were also active in promoting birth control. They included individuals such as Helen Bunn (1879–1951), a leader in the Community Chest, former member of Ramsey County's Welfare

<sup>322</sup> Sheldon C. Reed, "The Minnesota Human Genetics League, Part 4 of a Series." *Minnesota Medicine* 40 (1957): 128.

<sup>323</sup> S. Reed, "Human Genetics League, Part 4."

Board, and supporter of Neighborhood House in St. Paul (a settlement house); <sup>324</sup> Dorothy Bridgman Atkinson, board chairperson of the Minnesota Birth Control League, and Elizabeth Bates Cowles, birth control advocate and wife of the owner and publisher of both the *Minneapolis Tribune* and the *Minneapolis Star*. <sup>325</sup> Forty-seven people gathered for the first meeting of the Minnesota Human Genetics League in November 1945. Reed commented that none of the Minnesota Human Genetics League members was a "holdover from the old Minnesota Eugenics Society," and that although separate from the Dight Institute, the new organization completed "the fourth and final requirement of the Dight bequest." Reed foresaw that as the original officers of the League, all of them University of Minnesota professors, resigned or retired, people external to the university would replace them and broaden its community base and social connections. <sup>327</sup> The new organization did not limit itself simply to fundraising for the Dight Institute. In keeping with the activist bent of its members, it also chose to engage in public relations and advocacy for human genetics.

Clarence Oliver's successor, Sheldon Reed, skillfully engaged the Minnesota

Human Genetics League in promoting public awareness for the Dight Institute and
advocating the cause of human genetics in Minnesota. The Minnesota Human Genetics

League provided financial, social, and political support to the Dight Institute in a variety
of ways sustained over time. It acted as a watchdog on the University of Minnesota itself
in regard to including human genetics in the curriculum, relieving staff at the Dight

<sup>&</sup>lt;sup>324</sup> Dwight Minnich, "In Appreciation of Helen Bunn," in Dight Institute *Bulletin no. 7*, (1951).

<sup>&</sup>lt;sup>325</sup> S. Reed, "Human Genetics League Part 4."

<sup>326</sup> S. Reed, "Human Genetics League, Part 2."

<sup>327</sup> S. Reed, "Human Genetics League, Part 2."

Institute of that politically delicate task. The Minnesota Human Genetics League also lobbied for controversial causes such as birth control and abortion law reform that the university could not publicly support.<sup>328</sup>

By 1956, Sheldon Reed was the only remaining university employee still holding office, as secretary, in the Minnesota Human Genetics League. The organization had grown to 125 members. Minnich served as president for fifteen years and was succeeded in 1960 by John S. Pearson, a psychologist at Rochester State Hospital; Mildred Thomson, the Secretary of the Minnesota Board of Control in 1961; Sheldon Reed in 1962; with the first community-based president Jane McCarthy in 1968<sup>330</sup>; followed by Polly Brown in 1972; and Lee E. Schacht, geneticist at the Minnesota Department of Health, in 1973. Minnesota 1973.

In 1969, the Minnesota Human Genetics League's officers proposed to expand the League's presence in the community by moving their offices from the university. They explored the possibility of office space with the Minnesota Department of Health, but ultimately rented space in downtown Minneapolis.<sup>332</sup> Lack of money forced them to abandon their downtown office and pull back to their base at the Dight Institute and in the

 $<sup>^{328}</sup>$  Sheldon C. Reed, in Dight Institute Bulletin no. 13, (1966).

<sup>329</sup> S. Reed, "Human Genetics League, Part 5."

<sup>&</sup>lt;sup>330</sup> Jane McCarthy, presidential address, minutes of 23<sup>rd</sup> annual meeting, Minnesota Human Genetics League, November 20, 1968, Papers of the Minnesota Human Genetics League, University of Minnesota Archives.

<sup>&</sup>lt;sup>331</sup> Typewritten draft of proposal for expansion, September 1968, Papers of the Minnesota Human Genetics League, University of Minnesota Archives.

<sup>332 &</sup>quot;Proposal, Minnesota Human Genetics League."

private offices and homes of the officers.<sup>333</sup> The idea of locating the Minnesota Human Genetics League at the Department of Health died a quiet death because the Commissioner was concerned that the League's involvement in abortion law reform and its "slant toward 'quality' population" would not be politically acceptable for an organization located within a state agency.<sup>334</sup>

The Minnesota Human Genetics League maintained pressure on the University of Minnesota Medical School to establish courses for medical students and physicians on human genetics. Some medical schools had been teaching genetics to their students since the 1930s. The 1969, Minnesota Human Genetics League president, Jane McCarthy, criticized leaders at the medical school because medical students received "no formal training in genetics." Medical school officials replied that a committee of departmental chairmen was looking into the issue, and they assured McCarthy that the "situation is not as bleak as [you] assumed, genetics being taught in several courses and departments." They promised that a new curriculum would include a required course in medical genetics. That outcome took five additional years to accomplish. In 1974, Reed wrote to Minnesota Human Genetics League members, "It has happened at long last!! Your

<sup>333</sup> Typewritten anonymous notes of meeting with Robert N. Barr, Minnesota Commissioner of Health, Minnesota Human Genetics League, January 5, 1970, Papers of the Minnesota Human Genetics League, University of Minnesota Archives.

<sup>&</sup>lt;sup>334</sup> Polly Brown to Pam Veerhusen, memorandum, typewritten notes from meeting October 6, 1969, Papers of the Minnesota Human Genetics League, University of Minnesota Archives.

<sup>&</sup>lt;sup>335</sup> Marge T. Macklin, "Should The Teaching Of Genetics As Applied To Medicine Have A Place In The Medical Curriculum?" *Journal of the Association of American Medical Colleges* 7 (1932): 368–73.

Jane McCarthy to Ellis Benson, Professor and Chairman of the University of Minnesota Department of Laboratory Medicine, in the *Geneal Gazette*, newsletter of the Minnesota Human Genetics League, vol. 1, no. 2, November 1969, Papers of the Minnesota Human Genetics League, University of Minnesota Archives.

<sup>337</sup> McCarthy to Benson.

secretary has hoped for a required course in human genetics for all medical students for twenty-seven years." Reed later expressed the opinion that, "the thing that kept human genetics out of medical schools was the failure of physicians to see that it had any practical use in the practice of medicine."

Faculty members Jorge Yunis, professor of laboratory medicine and pathology, and Robert J. Desnick (born 1943), an associate professor in cell biology and pediatrics, taught the first University of Minnesota Medical School course in human genetics in the spring of 1974. Desnick, who had received his Ph.D. at the Dight Institute in 1970 and his M.D. degree a year later, also served as an officer of the Minnesota Human Genetics League. Reed credited the League, saying, "Medical genetics is finally an established part of medical education at the University. Much of the credit for this comes from the persistent support of the Minnesota Human Genetics League of everything related to human genetics for the last thirty years." 340

## Members and Benefactors of the Minnesota Human Genetics League

Minnich's and Reed's hope to recruit financially and socially prominent members the Minnesota Human Genetics League highly succeeded. These well-connected and often wealthy members provided unflagging financial support for the Dight Institute and its programs, and the organization also benefited from their connections with Minnesota society and state decision-makers.

<sup>338</sup> Sheldon C. Reed, membership mailing, "Call for Dues," March 1974, unlabeled folder, Papers of the Minnesota Human Genetics League, University of Minnesota Archives.

<sup>&</sup>lt;sup>339</sup>Sheldon C. Reed to Kenneth M. Ludmerer, July 28, 1970, box 1, folder "Correspondence L," Dight Institute Papers, University of Minnesota Archives.

<sup>340</sup> Reed, "Call for Dues."

Elizabeth Bates Cowles (died 1976) proved to be a staunch supporter of the Minnesota Human Genetics League. Her husband, John Cowles, Jr., (1898–1983), Minneapolis newspaper publisher, had met Elizabeth while he was a student at Harvard and she was at Smith College.<sup>341</sup> In 1929, they returned to his hometown of Des Moines, Iowa, where his father and extended family had run the *Des Moines Register* since 1903. Elizabeth Cowles energetically supported liberal social causes in Des Moines and in 1935 helped start the first birth control clinic in Iowa.<sup>342</sup> The John Cowles, Jr., family moved to Minneapolis from Des Moines in 1938 when he bought the *Minneapolis Star* and the *Minneapolis Tribune*. Elizabeth continued to support causes important to her including Planned Parenthood of Minneapolis, the American Civil Liberties Union, the League of Women Voters, the United Negro College Fund, and the National Association for the Advancement of Colored People.<sup>343</sup>

In Minneapolis, Elizabeth Cowles, moved by the plight of the Cowles newspapers' African–American employees who could not find housing and disgusted by discrimination toward black soldiers who were serving in World War II, took on the cause of racial justice by serving on the board of the Minneapolis Urban League. In the Urban League's national publication in 1948, Cowles explained how she became interested in racial justice issues. At Smith College in 1916 she had been appalled at derogatory statements made by a white student to a black classmate in gym class. "The

<sup>&</sup>lt;sup>341</sup> "The Cowles Family: Four Generations," website of the Cowles Family Publishing Library, Drake University, http://www.lib.drake.edu/heritage/GardnerCowlesFamily/JohnCowles.html; accessed May 8, 2011.

<sup>&</sup>lt;sup>342</sup> James A. Alcott, *A History of Cowles Media Company* (Minneapolis, MN: Cowles Media Company, 1998).

<sup>&</sup>lt;sup>343</sup> Cowles Family Publishing Library website, accessed November 28, 2010.

southerner embarrassed us. No strong emotions were aroused. It was simply a question of manners." In the same article, Cowles explained the connection between racial justice and the issue of women's access to contraception,

Now I had long known that my own life was held cheap in two states. I knew that in Massachusetts and Connecticut I would have been denied preventive medical care to save my life or preserve my health as a wife and mother of four children. I felt a bond with colored people whose lives are held cheap in varying degrees in forty-eight states."<sup>344</sup>

Years later, an observer remembered her stories of standing in front of Minneapolis City Hall in the early 1940s daring police to arrest her for handing out birth control information and being disappointed when they refused.<sup>345</sup>

Betty Cowles remained a member of the Minnesota Human Genetics League Board of Directors until 1962, resigning in a personal note to Sheldon Reed,

Both John and I believe strongly in [the Minnesota Human Genetics League's] work and are proud of its achievements. In addition we are grateful for the knowledge we have at least been exposed to by you and other experts in the field. Our interest as members will continue. After all, we are CHARTER MEMBERS AND PROUD OF IT [her capitalization]."<sup>346</sup>

In addition to her financial contributions, Cowles helped the Minnesota Human Genetics

League in other ways, for example using her family and social connections (stepdaughter
to the Chairman of the Editorial Board of Harpers & Company in New York) to garner
favorable attention for Sheldon Reed's work and to obtain opportunities for him to write

<sup>&</sup>lt;sup>344</sup> Elizabeth Cowles, "How I Became Interested in Racial Justice" in *Opportunity*, Winter, 1948, reprinted in James A. Alcott, *A History of Cowles Media Company*.

<sup>&</sup>lt;sup>345</sup> Lee E. Schacht interview by Neal Ross Holtan, October 7, 2007, available from author in digital audio or transcription formats; transcript (digital audio pending), Oral History Collection, University of Minnesota Archives.

<sup>&</sup>lt;sup>346</sup> Handwritten letter, Elizabeth Cowles to Sheldon C. Reed, July 30, 1962, box 1, folder "Correspondence C," Dight Institute Papers, University of Minnesota Archives.

books about human genetics for a mass audience.<sup>347</sup> Most importantly, Sheldon Reed credited Cowles with recruiting most of the members of the Minnesota Human Genetics League.<sup>348</sup>

Another Minnesota Human Genetics League leader was Polly Brown. Born Olive Crosby Case, but called Polly, a member of the wealthy Minneapolis milling Crosby family, Brown represented a younger generation of members and leaders than had Betty Cowles. Brown's life story seemed to reflect the arc of some women's lives during the 1960s and 1970s; she dropped out of Smith College after two years (befriending the poet Sylvia Plath there), married at 20, and was divorced at age 26. In the early 1960s with three young sons and no career, she volunteered in the community and discovered that she had unrealized leadership talent. First volunteering to sit with sick children at St. Barnabas Hospital in downtown Minneapolis, Brown moved to the Minneapolis Planned Parenthood clinic where she met state and national leaders in the birth control movement. She presided over the process that formed the statewide Planned Parenthood organization in 1965 and led the organization until 1971. As a remarried mother, a community volunteer, health activist, one of the first women to sit on the board of directors of a major Minnesota corporation, and chairperson of the Guthrie Theater's Board of Directors, Polly Brown told a feature newspaper reporter that she had a predilection "for presiding over things."349 She joined the Minnesota Human Genetics League around

<sup>&</sup>lt;sup>347</sup> Cass Canfield to Sheldon C. Reed, December 16, 1955, box 1, folder "Correspondence C," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>348</sup> S. Reed, "Minutes of Annual Meeting, 1976."

<sup>&</sup>lt;sup>349</sup> Carole Nelson, "Polly Brown is Making Headway Against Current," September 10, 1976, *St. Paul Pioneer-Press*, St. Paul, MN, 7.

1965, chaired the officer nominating committee in 1968, and served as president for a year in the early 1970s.<sup>350</sup>

### The Minnesota Human Genetics League's Causes

The Minnesota Human Genetics League employed an entirely different strategy to achieve eugenic goals than had Dight's Minnesota Eugenics Society. It avoided promoting restrictive and intrusive legislation, such as the 1925 sterilization act, and focused instead on positive aspects of human genetics. Reed had the League's support in publicizing human genetics through positive mass media messages. This direction was consistent with Frederick Osborn's strategy for the American Eugenics Society in deemphasizing old, unpopular concepts of negative eugenics and placing increased importance on more upbeat topics such as finding solutions to problems of population genetics. The Minnesota Human Genetics League did not have any relationship with the national American Eugenics Society or its leaders.

The Minnesota Human Genetics League supported research on population genetics. In 1953, the League funded an analysis of Huntington's disease in Minnesota. In that study, John S. Pearson, research psychologist at Rochester State Hospital, built on the work of one of the Dight Institute's graduate students, J. Daniel Palm. He used an additional grant from the Hill Family Foundation to study the feasibility of establishing a

<sup>&</sup>lt;sup>350</sup> Membership list, 1968, and Internal Revenue Service Tax Form, 1965, Papers of the Minnesota Human Genetics League, University of Minnesota Archives.

<sup>351</sup> Sheldon C. Reed, "The Minnesota Human Genetics League, Part 6 of 6" *Minnesota Medicine* 40 (1957): 265–66.

<sup>&</sup>lt;sup>352</sup> Edmund Ramsden, "Eugenics from the New Deal to the Great Society: Genetics, Demography and Population Quality," in *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences* 39, no. 4 (2008): 391–406; Frederick Osborn, *The Future of Human Heredity: An Introduction to Eugenics in Modern Society* (New York, NY: Weybright and Talley, 1968).

statewide registry and census of Huntington's disease.<sup>353</sup> The Minnesota Human Genetics League provided Pearson with funds to create and distribute 5,000 copies of a pamphlet about Huntington's disease for affected families. The pamphlet gained wide popularity in Minnesota and throughout the United States. With League backing, Pearson also produced films of Huntington disease patients before and after they received the drug reserpine, movies that showed remarkable improvement in their symptoms. In 1953, Pearson formally proposed to Sheldon Reed a complete, statewide Minnesota Huntington's disease registry to provide information about the affected families to inform them about disease risk. The statewide registry, however, did not transpire until after 1960 when it became part of public health genetics.<sup>354</sup>

One of the Minnesota Human Genetics League's purposes was to publicize the results of human genetic research conducted by the Dight Institute. It also directly funded large and small ongoing research projects. One of the largest was a study of mentally retarded inmates at the School for the Feeble-Minded conducted by Elizabeth and Sheldon Reed. Starting with residents at Faribault between 1911 and 1918, Elizabeth Reed painstakingly traced hundreds of their offspring in 300 families with up to 500 members each to study familial patterns and rates of mental deficiency. The Minnesota Human Genetics League made it financially possible for Elizabeth Reed to travel to

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<sup>&</sup>lt;sup>353</sup> I found no documentation to show that members of the Minnesota Human Genetics League provided support for Pearson's application for the grant from the Hill Family Foundation.

<sup>&</sup>lt;sup>354</sup> Ramsden, "New Deal to Great Society."

<sup>&</sup>lt;sup>355</sup> Elizabeth W. Reed and Sheldon C. Reed, *Mental Retardation: A Family Study* (Philadelphia, PA: W.B. Saunders Co., 1965).

<sup>&</sup>lt;sup>356</sup> Elizabeth and Sheldon Reed, *Mental Retardation*.

Copenhagen with her husband in August 1956 to the First International Congress on Human Genetics where she reported the findings from that study.<sup>357</sup>



Figure 7. Reed Family (Sheldon, Elizabeth, Catherine, and William) traveling aboard the M.S. *Bergensfjord* to attend the First International Congress of Human Genetics, 1956. (University of Minnesota Archives)

In addition to research, the Minnesota Human Genetics League provided money to bring scholars and authorities in human genetics to Minnesota annually for a public lecture. Speakers included Laurence H. Snyder (1901–1986), early expert in medical genetics, <sup>358</sup> and Theodosius Dobzhansky (1900–1975), *Drosophia* geneticist who used

<sup>&</sup>lt;sup>357</sup> Sheldon C. Reed, in Dight Institute *Bulletin no. 10*, (1957).

Nathaniel Comfort, "'Polyhybrid Heterogeneous Bastards': Promoting Medical Genetics in the 1930s and 1940s," *Journal of the History of Medicine and Allied Sciences* 61 (2006): 415–55; doi:10.1093/jhmas/jrl001.

field studies to research and analyze the frequency of mutations.<sup>359</sup> Minnesota Human Genetics League members themselves maintained an active speakers bureau and presented talks to groups as varied as "secondary school children, PTA groups, church groups, selected college groups, women's clubs, and other lay organizations."<sup>360</sup>

The Minnesota Human Genetics League and the Dight Institute also promoted population genetics. In 1948, the two organizations, with funding from the Carnegie Corporation of New York and Elizabeth Cowles in Minneapolis, held a conference in Minneapolis on global over-population called the "Symposium on Populations and Relationships Between Groups." Speakers from universities throughout the United States presented five days of talks about population issues and trends in the United States and the under-developed world, the social and economic effects of over-population, and possible effects of over-population on population genetics. Presenters defined what they considered the optimal human population for the planet and calculated "roughly how much food, clothing and shelter, leisure time and community resources, are needed per person to ensure a healthy progressive society." Elizabeth Cowles hosted a reception for the speakers and attendees at her Park Avenue Minneapolis home. The Second

<sup>&</sup>lt;sup>359</sup> Harper, A Short History, 92.

<sup>&</sup>lt;sup>360</sup> Typewritten document, proposal by the Human Genetics League, circa 1969, Papers of the Minnesota Human Genetics League, University of Minnesota Archives.

<sup>&</sup>lt;sup>361</sup> Sheldon C. Reed, "The Minnesota Human Genetics League," *Minnesota Medicine* 40 (1957): 265–266.

<sup>&</sup>lt;sup>362</sup> Sheldon C. Reed, Dight Institute *Bulletin no. 6*, (1949).

<sup>&</sup>lt;sup>363</sup> Announcement of conference, November 8–13, 1948, folder "Population Conference," Papers of the Minnesota Human Genetics League, University of Minnesota Archives.

<sup>364</sup> Sheldon C. Reed, report of the secretary–treasurer, minutes of the annual meeting of the Minnesota Human Genetics League, November 18, 1976, Papers of the Minnesota Human Genetics League, University of Minnesota Archives.

conference, in 1957, focused on population and the limitation of the earth's resources. The University of Minnesota's Ancel Keys (1904–2004) spoke about minimal human food sustenance for certain numbers of human beings, and Frederick Osborn, now affiliated with the Population Council, talked about optimal human populations. Osborn, elected president of the American Eugenics Society in 1946, represented the "old" eugenics and the escalating trend to transform it into population genetics and genetic quality.

## **Birth Control and the Population Explosion**

After World War II, the birth control movement encountered two powerful social trends, first the new emphasis on world population control and the second, the adoption of the oral contraceptive pill. While the birth control movement had previously centered on women's rights and feminism, the population control movement was based a different set of values, namely, Malthusian fears about the earth's ballooning population and the effect it could have on human health, including genetic quality. Starting in the 1940s, the Milbank Memorial Fund, a supporter of the eugenics movement, in particular the American Eugenics Society, shifted its resources into research about overpopulation. In 1952, Frederick Osborn, the director of the American Eugenics Society, started the Population Council, and his cousin, Fairfield Osborn (1887–1969), environmentalist and the president of the New York Zoological Society, led Planned Parenthood—World Population. Milbank, joined by the Rockefeller Foundation, funded

<sup>&</sup>lt;sup>365</sup> "Population Conference."

<sup>&</sup>lt;sup>366</sup> Linda Gordon, *The Moral Property of Women: A History of Birth Control Politics in America*, (Urbana, IL: University of Illinois Press, 2002): 279–91.

<sup>&</sup>lt;sup>367</sup> Gordon, *Moral Property*. 281.

Princeton University, the alma mater of both of the Osborns and John D. Rockefeller, to organize the Office of Population Research. That center attracted a group of eugenicist demographers such as Kingsley Davis and Frank Notestein, five of whom moved to Frederick Osborn's Population Council after he founded it. With these events, the eugenics establishment took over the population control movement and gave Planned Parenthood a new cause and purpose that was popular with national politicians. 368

As historian Linda Gordon has stated, "From the marriage of birth control and population control came a robust child: the contraceptive pill." Margaret Sanger's friend and supporter since 1917, wealthy heiress Katherine McCormick, asked her in 1950 what she could support as a grand project. She gave Sanger \$2 million to develop an oral contraceptive pill privately. A half million women in the United States were already "on the pill" before the Food and Drug Administration approved it as a contraceptive in 1960. Sanger's dream of a safe and effective method of birth control for over-populated poor countries had greater—and unintended—consequences in the United States, providing women with the tool to achieve "autonomy, freedom, and higher aspirations." 370

#### Birth Control in Mid-Twentieth Century Minnesota

The Minnesota Human Genetics League and the Dight Institute had strong connections with the birth control movement in Minnesota. The League's membership largely overlapped with members and leaders of Minnesota's birth control movement

<sup>&</sup>lt;sup>368</sup> Gordon, *Moral Property*, 281.

<sup>&</sup>lt;sup>369</sup> Gordon, *Moral Property*, 286.

<sup>370</sup> Gordon, Moral Property, 288.

such as Cowles and Brown. Some people served several roles, for example, Dwight Minnich, professor of zoology, chairman of the Dight Institute Advisory Committee and president of the Minnesota Human Genetics League (for fifteen years), was a member of the Board of Directors of Planned Parenthood of Minnesota (from 1948 until 1964). In another example of inter-related roles in these organizations, Sheldon Reed served as a board member of Planned Parenthood from 1948 through 1958.<sup>371</sup>

An example of these organizations operating in tandem occurred in January 1951 when William Vogt (1902–1968), Director of Planned Parenthood Federation of America, paid a two-day visit to Minnesota. The event, orchestrated by Minnich as President of the Minnesota Human Genetics League, included lunch at the University of Minnesota's Campus Club with a few key Minnesota Human Genetics League members, a tour of the Dight Institute by Sheldon Reed in the afternoon, dinner at the Minnichs' home for Vogt and members of the Minnesota Human Genetics League Board of Directors and their spouses, and a lecture by Vogt to the general membership of Minnesota Human Genetics League on campus at 8 o'clock that evening. The following day, Vogt attended a luncheon meeting of the Hennepin County League for Planned Parenthood. The rotation of individuals through leadership positions in the Minnesota Human Genetics League, birth control advocacy organizations, and women

<sup>&</sup>lt;sup>371</sup> Sheldon C. Reed, curriculum vitae, 1969, attached to letter to R.T. Ravenholt, box 1, folder "Committee on Population Studies 1967–69," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>372</sup> Dwight Minnich to William Vogt, December 27, 1951, box 1, folder "Dwight Minnich," Dight Institute Papers, University of Minnesota Archives.

Minnich to Vogt, December 21, 1951.

and children's welfare groups to one later observer resembled a game of musical chairs.<sup>374</sup>

# A Short History of the Birth Control Movement in Minnesota and the United States

Organizations to support access to birth control for poor women arose spontaneously and seemingly without instigation by national organizations throughout the United States in the 1920s. The socially prominent Minneapolis women started the Minnesota Motherhood Protection League in 1928. Access to contraception had been severely curtailed in the United States by the Comstock Act of 1873 that made it illegal to send birth control information or devices through the United States Postal Service. Minnesota also passed a law that made the manufacture, promotion, and sale of contraceptives illegal, punishable with a \$500 fine. The law in Minnesota had a loophole that allowed physicians to prescribe birth control devices to cure or prevent disease, meaning that women of means who could afford a private physician could easily obtain contraceptives, usually a diaphragm, and men could access condoms. The Poor women had no legal access to birth control devices in Minnesota.

Differences in socio–economic class led to marked disparities in access to birth control in the United States during the first half of the twentieth century.<sup>377</sup> In 1922, sociologist Katherine Bement Davis (1860–1935) interviewed 1,000 married college alumnae and members of women's clubs and found that nearly 75 percent used

<sup>&</sup>lt;sup>374</sup> Interview with Lee E. Schacht.

<sup>&</sup>lt;sup>375</sup> Linda Gordon, "The Struggle For Reproductive Freedom," in *Controlling Reproduction: An American History*, ed. Andrea Tone (Wilmington, DE: Scholarly Resources, Inc, 1997), 147–55.

Minnesota General Statutes, 1891, sec. 6234.

David Kennedy, "The Debate on Morality," *Birth Control in America: The Career of Margaret Sanger* (New Haven, CT: Yale University Press, 1970), 136–71.

contraceptives.<sup>378</sup> The Middletown, USA, study in the mid-1920s showed that affluent subjects were more likely to use birth control than poorer women. On the other hand, even affluent practitioners of contraception in the 1920s were reluctant to discuss the topic of birth control in public and the mass media completely avoided the subject.<sup>379</sup>

Members of the Motherhood Protection League met regularly to share information about the national birth control movement, advocate for access to legal contraception, and enjoy music and refreshments. The socializing belied their fierce dedication to legalizing birth control and providing access for the poor. In 1930, five hundred members and supporters of the Motherhood Protection League petitioned the Minnesota Council of Social Agencies, the board responsible for planning for the Community Chest (forerunner of the United Way), to open a birth control clinic and provide information about contraception to poor women. The request was tabled with no explanation. In 1931, the Motherhood Protection League, their name changed to the Minnesota Birth Control League, opened a birth control clinic in downtown Minneapolis staffed by a physician, a nurse, and a secretary; the League supported the clinic with donations and held social events such as lectures, plays, and musical presentations to raise money for it. 381 Within six years, additional clinics opened in St. Paul, Rochester,

<sup>&</sup>lt;sup>378</sup> Katherine Bement Davis, "A Study Of The Sex Life Of The Normal Married Woman," Part I: "The Use of Contraceptives," *Journal of Social Hygiene* 8 (1922): 173–89.

<sup>379</sup> Kennedy, Birth Control in America.

<sup>&</sup>lt;sup>380</sup> Mary Losure, "'Motherhood Protection' and the Minnesota Birth Control League," *Minnesota History* (Winter 1995): 359-70.

<sup>381</sup> Losure, "Motherhood Protection."

Duluth, Hibbing, and Bagley, and on the south side of Minneapolis to serve African American women.<sup>382</sup>

Members of the Motherhood Protection League included some of the most socially prominent women in Minneapolis, including Eleanor Lawler Pillsbury (1887–1991), married to one of the Pillsbury grain milling company's executives and heirs; Nelle Pendleton Pillsbury (1878–1957); and Elizabeth Bradley Heffelfinger (1900–1981), a member of the Peavy grain company family and National Republican

Committeewoman for twelve years. Its president for most of the 1930s was Dorothy B.

Atkinson, the daughter of a former Hamline University president and wife of an executive with the Washburn–Crosby milling concern. Elizabeth Cowles joined the board of the Motherhood Protection League soon after moving to Minneapolis in 1938.

Cowles's son, John III, later remembered Dorothy Atkinson as "big, noisy, and even more outspoken" than his mother, completely dedicated to the cause of birth control, and the recipient of frequent anonymous abusive telephone calls that she resolutely ignored.

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Stiff opposition to birth control in Minnesota came from the Roman Catholic archbishop of St. Paul, John Gregory Murray (1877–1956), who ordered in 1935 that Catholic women in the Archdiocese of Minnesota, the Dakotas, and Montana be excommunicated if they did not withdraw from all organizations favoring birth control or sterilization. He likened such organizations to the Dillinger gang, "organized to commit murder." Murray was the first archbishop in the United States to order excommunication

<sup>382</sup> Losure, "Motherhood Protection."

<sup>383</sup> Losure, "Motherhood Protection."

for that cause; his brother bishops failed to endorse his strategy at their annual meeting, recommending instead that Catholic women be urged to resist or rescind pro-birth control resolutions passed by women's groups such as the National Federation of Women's Clubs. Archbishop Murray periodically called meetings with leaders of the Community Chest and Council, the forerunner of United Way, whenever Planned Parenthood of Minnesota attempted to become one of the funded charities. Planned Parenthood did not receive financial support from United Way until 1958, after the Archbishop's death.

Opposition and legal roadblocks to contraception started to crumble in the United States after the 1936 Supreme Court ruled that the Comstock law was unconstitutional. In another change the following year, the American Medical Association officially adopted the position that contraception was a legitimate part of medical practice. Birth control supporters argued that access to contraception was an important public health issue and it could save lives lost to abortion and prevent adverse consequences of unwise, unwanted pregnancies. In 1940, Eleanor Roosevelt publicly voiced her support for contraception, and during the war years, the United States Public Health Service began to fund birth control programs.<sup>386</sup>

The end of legal restrictions on birth control in Minnesota came in 1965 with United States Supreme Court decision in *Griswold v. Connecticut* that struck down that state's law against physicians providing birth control information and services to married

<sup>&</sup>lt;sup>384</sup> Leslie Woodcock Tentler, *Catholics and Contraception: An American History* (Ithaca, NY: Cornell University Press, 2004), 128.

<sup>&</sup>lt;sup>385</sup> Tentler, Catholics and Contraception.

<sup>&</sup>lt;sup>386</sup> Gordon, *Moral Property*, 245.

couples. The Minnesota legislature unanimously voted to repeal the archaic 1886 law that was based on the same anti-obscenity arguments that were the basis of the Comstock law.

In spite of changes in laws and society, inaccessibility of birth control for the poor remained until federal funds were allocated for that purpose. Limited funding was available to local public health departments under the United States Department of Health, Education, and Welfare's Children's Bureau. The application for that funding at the local public health department in St. Paul in 1969, noted, "While any and all forms of birth control were available for private patients from their private doctors, indigent patients as a consequence of these prohibitions had no facilities open to them except in isolated instances." Title X of the Public Health Service Act of 1970 provided expanded funding and nationwide coverage for contraceptive services for the poor.

# **Public Policy Achievements of the Minnesota Genetics League**

The capstone achievement of the Minnesota Human Genetics League, acknowledged by Sheldon Reed among many others, was to shepherd a law through the legislature in 1959 that authorized the state health department to create a Human Genetics Unit. The purpose of the unit was to provide and assure genetic services to the entire population of Minnesota. Minnesota Human Genetics League members worked closely with academic leaders, social advocacy groups, and organizations representing families affected by genetic disorders to bring pressure on the legislature to enact a law to incorporate human genetics into the responsibilities of the health department. This

<sup>&</sup>lt;sup>387</sup> Application to the United States Department of Health, Education, and Welfare, Social and Rehabilitation Service, Children's Bureau, from the St. Paul Bureau of Health, June 25, 1969. This grant funded the earliest public health birth control clinic in Minnesota. Mary Sonnen and Sheila Penzel, its two directors to date, provided the author with a copy of the original grant proposal from their files at St. Paul–Ramsey County Public Health in February 2010.

application of human genetics to an entire defined population as a function of state government was an innovation that became a national model, the first application of genetic science as a public health program in the United States. The health department in Minnesota in 1960 became the first to employ a fulltime human geneticist, Lee E. Schacht. In recollecting those early years, Schacht described having to invent the content of public health genetics day to day because there were no models or precedents.<sup>388</sup>

Sheldon Reed made one of the earliest suggestions that genetic diseases be considered as public health issues. In 1953, he proposed a network of one hundred heredity clinics in the United States.

There is no question in our minds but that the heredity clinic performs a valuable public service which should be free to the client, and that the clinic should be at a university. To the orderly minded, it would seem that this public service should be financed from taxes and perhaps by the US Public Health Service.<sup>389</sup>

In other words, Reed proposed that genetic counseling be a public, governmentally supported service accessible to everyone regardless of financial means.

The case for a public health approach for preventing Huntington's disease was similar to the concept of providing universal access to genetic counseling yet it differed in providing enhanced services to particular families at high risk, defined as a subset of the population with Huntington's disease in the family. The public health tool of disease registries fit well with preventing Huntington's disease and was among the earliest concepts for addressing a hereditary condition across the entire population. In 1953, Sheldon Reed wrote,

 $^{389}$  Sheldon C. Reed, "Counseling in Human Genetics, Part III," in Dight Institute *Bulletin no.* 8, (1953).

<sup>&</sup>lt;sup>388</sup> Interview with Lee E. Schacht.

As a primary step in an extensive program of research in all three areas—description, prediction, and control of the disorder—I feel that an effort should be made in the immediate future to compile a register of all known past, present, and potential victims of the disease in this state.<sup>390</sup>

Sheldon Reed therefore took a position about disease registries in 1953 that became one of the most effective arguments for the establishment of public health genetics.

#### The Drive to Secure Authorization for a State Human Genetics Unit

In March 1958, Sheldon Reed proposed to the executive secretary of the Minnesota Board of Health, Robert N. Barr, that a human genetics unit be developed at the state health department.<sup>391</sup> He wrote:

The epidemiology of genetic diseases is as exciting as that of diseases due to parasites. The work of Dr. John S. Pearson on the epidemiology of Huntington's chorea in Minnesota is an excellent illustration of both the practical and theoretical returns to be expected from a small investment. Because of his work as well as the development here of genetic counseling, Minnesota has become known throughout the world for the successful utilization of human genetics for the public good.

Reed's personal agenda in recommending a state-run service for genetic counseling was partly driven by being overburdened with requests for it at the University of Minnesota. He stated to Barr that genetic counseling had progressed beyond the "strictly research status it had and has turned into a health service no different from that in many of the branches of your department." Genetic counseling was so successful that it was no longer a research activity that needed the support of the university. In Reed's opinion, genetic counseling was "definitely now in the service field and rightfully should be administered by the Department of Health" for the benefit of the entire population of Minnesota. He

<sup>&</sup>lt;sup>390</sup> S. Reed, "Counseling in Human Genetics."

<sup>&</sup>lt;sup>391</sup> Sheldon C. Reed to Robert N. Barr, March 26, 1958, box 1, folder "Correspondence B," Dight Institute Papers, University of Minnesota Archives.

estimated a cost of \$15,000 to establish a human genetics unit, including a geneticist at the third level research scientist classification of government service, a full time secretary, and support for travel, supplies, and other expenses. Reed suggested that this minimal budget would support a new scientist with a Ph.D. degree, but if Minnesota were to "be a model for other states, a more experienced geneticist would be required." <sup>392</sup> Barr apparently found Reed's arguments convincing and designated \$15,000 in the state health department's budget to establish a Human Genetics Unit along the lines that Reed had proposed. His only reservation was that he and his staff thought that they lacked specific authority from the legislature for such action. <sup>393</sup>

Getting legislative authority for the state health department to provide genetic services was a task well suited to the members of the Minnesota Human Genetics League. <sup>394</sup> Its secretary, Sheldon Reed and its president, John Pearson, and the members of the executive committee took on the challenge. They appointed an ad hoc committee of five Minnesota Human Genetics League members, led by Letha Patterson of St. Paul, mother of a mentally retarded child, to persuade the legislature to make public health genetics an official part of governmental activity in Minnesota. <sup>395</sup> Patterson, a member of the St. Paul Association for Retarded Children and a founding member of the National

<sup>&</sup>lt;sup>392</sup> Reed to Barr, 1958.

<sup>&</sup>lt;sup>393</sup> Letha L. Patterson, memorandum to Paul Christopherson, John S. Pearson, Sheldon C. Reed, and V. Elving Anderson, March 24, 1959, box 3, folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>394</sup>Sheldon C. Reed, mass mailing to members of Minnesota Human Genetics League, June 15, 1959, Papers of the Minnesota Human Genetics League, University of Minnesota Archives.

<sup>&</sup>lt;sup>395</sup> Letha L. Patterson, "Some Pointers for Professionals," *Children*, January–February, 1956, United States Department of Health, Education and Welfare, reprinted in *Mental Retardation: Readings and Resources*, ed. Jerome H. Rothstein (New York, NY: Holt, Rinehart and Winston, 1962); Sheldon C. Reed, in Dight Institute *Bulletin no. 11* (1959).

Association for Retarded Children (established in 1950), was active as an advocate for mentally retarded children and their families. Her work to educate health professionals about enlisting the help of parents had been highlighted at a national conference on counseling for parents of retarded children held in Minneapolis in May 1958, cosponsored by the Woods Schools for Exceptional Children and the University of Minnesota. Charles W. Mayo provided the welcome and John W. Bystrom, a professor at Hamline University and President of the Minnesota State Board of Education delivered the keynote speech entitled, "The Parent Counselor: An Emerging Resource," in which he mentioned Patterson's work with the national organization. 397

The law authorizing the Human Genetics Unit at the state health department took shape when Reed sent an outline of a proposed bill to Minnesota Human Genetics League member Paul Christopherson, an attorney at a large downtown Minneapolis's law firm. Because the legislative session was well underway, Christopherson moved quickly to draft the bill and send it to Letha Patterson. She worked closely with officials at the state health department, including R. N. Barr, the executive secretary; Jerome W. Brower, the

<sup>&</sup>lt;sup>396</sup> Patterson was listed as representing the St. Paul Association for Retarded Children on the Advisory Committee of "Sheltering Arms: A Day School and Research Program for Mentally Retarded Children," in their agency brochure, archived by the Minnesota Governor's Council on Developmental Disabilities, http://www.mnddc.org/past/pdf/50s/55/55-TSA-MNF.pdf, accessed February 26, 2011; for the history of the National Association for Retarded Children, see James W. Trent, Jr., "The Remaking of Mental Retardation: Of War, Angels, Parents, and Politicians," in *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (Berkeley, CA: University of California Press, 1994), 225–68.

<sup>&</sup>lt;sup>397</sup> John W. Bystrom (1958), "The Parent Counselor: An Emerging Resource," *Counseling Parents Of Children with Mental Handicap in the Proceedings of the 33rd Spring Conference of the Woods School Conference (in Cooperation with the University of Minnesota)*, Minneapolis, MN, May 2–3, 1958, (Langhorne, PA: The Woods Schools), archived by the Minnesota Governor's Council on Developmental Disabilities. http://www.mnddc.org/parallels2/pdf/50s/58-CPO-TWS.pdf, accessed February 24, 2011.

<sup>&</sup>lt;sup>398</sup> Sheldon C. Reed to Paul Christopherson, undated, box 3, folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.

department's Deputy Executive Officer and legal counsel<sup>399</sup>; his assistant, Eugene Larson; and A.B. Rosenfield, the physician in charge of the maternal and child division, to insure that the bill met their approval. They positioned the bill as a simple measure to meet the health department officials' wish for legal authorization to work on genetics, and they emphasized that the bill did not add expenses other than the \$15,000 line item already budgeted.

Reed developed arguments for the ad-hoc committee and other League members to use in convincing legislators to authorize the human genetics unit. First, establishing a human genetics unit in its health department would position Minnesota as progressive and the first state to authorize its board of health to pay attention to genetic diseases. Furthermore, the legislature's past support of genetic studies in animals had reaped huge financial dividends for Minnesota through improved agricultural productivity and increased tax revenue. A small investment in human genetics could save the state the cost of caring for individuals with genetic afflictions. Finally, they could cite the need for education for doctors and for the public about human genetics, a task too enormous for the University of Minnesota to accomplish. A human genetics unit at the health department would be a solution to these difficult problems.

Christopherson modeled the proposed law after one in Minnesota that had previously authorized the executive branch of government to study the issue of

Elisabeth Emerson, *Public Health Is People: A History of the Minnesota Department of Health from 1949 to 1999* (Minneapolis, MN: The Minnesota Department of Health, 2009), available only in electronic version from the Minnesota Department of Health upon request, 136. Jerome Brower became ill during the time when the Minnesota Human Genetics League members brought their bill to the Minnesota Legislature. He died of a streptococcal infection on May 28, 1959 at the age of 42.

<sup>&</sup>lt;sup>400</sup> Reed to Christopherson, undated.

alcoholism. He added a provision to the genetic law similar to one in the alcohol bill that mandated a committee of experts and citizens to advise the state health department. That advisory committee would insure fair, wise, and effective input about the public health genetics work and prevent actions detrimental to individual citizens.

The Minnesota Human Genetics League's ad hoc committee quickly approved the final draft of the bill, and Patterson contacted Barr and his staff for input. They suggested only a few minor format and language changes. Patterson warned the other members of the ad hoc committee that the health department officials were pessimistic about the bill's chances of passing in light of the state's budget problems and the short time available to introduce and hear the bill. On the other hand, Patterson had received intensive practical assistance from health department staff, especially from Eugene Larson, who helped with the logistics of obtaining legislative sponsors and introducing the bill before the committee deadlines. They all agreed that even though the bill might be voted down, it was good strategy to raise it. Add Patterson reflected their uncertainty,

Anything can happen, of course, and if we don't make it this time, [sic] guess we can salve ourselves with the thought that at least the groundwork is done for next session. It is unfortunate that we couldn't operate like a genuine committee by the ticking of the clock—so goofs will just have to be goofs.

Her last phrase apparently referred to the relative inexperience of Minnesota Human Genetics League members at crafting legislation, getting it through committees, and lobbying for passage. The legislative process, however, whether due to the soundness of

<sup>&</sup>lt;sup>401</sup> Paul Christopherson to Letha L. Patterson, February 12, 1959, box 3, folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>402</sup> Patterson memorandum, February 24, 1959.

<sup>&</sup>lt;sup>403</sup> Patterson memorandum, February 24, 1959.

the proposed legislation, the rightness of the cause, or the lack of organized opposition, went well for the proposed bill.

The Minnesota Human Genetics League, Sheldon Reed, and health department officials devoted a large amount of effort lobbying to get the bill passed. Reed, as secretary, wrote to the members of the Minnesota Human Genetics League on their letterhead describing the proposed legislation, naming the chairpersons and members of the appropriate legislative committees, and asking that members contact their legislators to support the bill. 404 John Pearson wrote to his legislative representatives from Rochester to get their backing for the bill. 405 Minnesota Human Genetics League member Gerald F. Walsh, the Executive Director of the Minnesota Association for Retarded Children, scheduled lunch meetings with key legislators, including Representative Everett Battles, the chairman of the Health Committee of the Minnesota House of Representatives, to get their support. He learned that Battles was enthusiastic about the bill and intended to move it out of committee quickly. 406

Mary Mercer of Owatonna, member of the Minnesota Human Genetics League, certified psychologist at Rochester State Hospital, and a constituent of Representative Battles's, wrote him in support of the proposed bill. She used many of the arguments suggested by Reed in her letter. Mercer extolled the success of Reed and the Dight Institute in preventing "sheer human misery" and emphasized her experience in

<sup>&</sup>lt;sup>404</sup> Sheldon C. Reed to members of the Minnesota Human Genetics League, April 3, 1959, box 3, folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.

John S. Pearson to Representative Donald Franke and Senator A. M. Keith, March 28, 1959, box 3, folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>406</sup> Gerald F. Walsh to Sheldon C. Reed, April 7, 1959, box 3, folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.

Rochester that the state would save thousands of dollars that otherwise would eventually be spent on caring for victims of Huntington's disease and other genetic conditions. She ended her letter with what she called an "atoms and all that" argument, namely, that the state health department could not monitor for possible genetic damage from radiation without a system of genetic surveillance. She wrote,

It is not too late to start such studies now, and what with strontium 90, it is not a minute too soon. We are really on the threshold of knowledge about this subject. By passing this bill Minnesota might well place itself out in front as a state which recognizes its responsibility to the future as well as the present."<sup>407</sup>

Another supporter of the bill, Professor and Head of the University of Minnesota Medical School's pediatrics department, John A. Anderson, wrote to Representative Battles, calling the bill an "investment, . . . the financial benefits to accrue and repay the state many times over." He referred to phenylketonuria (PKU) as a disease for which genetic counseling might prevent the birth of additional affected children in a family who would need lifetime institutionalization and that genetic counseling for the family after one child was identified with PKU would save the state a large amount of money. Anderson argued that the proposed human genetics unit was justified on this basis alone. 408

At the hearing in the state House of Representatives, Eugene Larson assured members of the health committee that the United States Public Health Service and the Atomic Energy Commission would likely provide additional funding for the proposed human genetics unit beyond the \$15,000 already contained within the department's

<sup>&</sup>lt;sup>407</sup> Mary L. Mercer to Rep. Everett Battles, April 6, 1959, box 3,folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>408</sup> John A. Anderson to Rep. Everett Battles, April 6, 1959, box 3, folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.

budget. Pearson, Reed, and Patterson testified in the bill's favor, and no one testified against it. The bill passed unanimously in both the House and Senate committees and in the legislature itself and became law on April 24, 1959 with the signature of Governor Freeman.<sup>409</sup>

## **Human Genetics Advocacy and Population Health**

Whether Charles Dight would have recognized the Minnesota Human Genetics

League as the eugenics society he had envisioned cannot be known. On the other hand,

Sheldon Reed certainly considered it to be just that. The Minnesota Human Genetics

League had similarities with Dight's Minnesota Eugenics Society in striving to improve
the gene pool through collective action and legislation. When the legislature authorized
the Human Genetics Unit in the health department in 1959, no one foresaw what that
meant or how the work would evolve. If the outcomes were eugenic in improving the
quality of the human gene pool in Minnesota, then the programs themselves would need
to yield the evidence.

 $<sup>^{\</sup>rm 409}$  Minnesota House of Representatives Files, HF 1513 (1959).

#### CHAPTER 5

#### **Public Health Genetics in Minnesota**

Public health is an organized community program designed to prolong efficient human life. It has no artificial limitations that would restrict its activities to certain types of problems. It must deal with and endeavor to combat those forces that tend to impair or to shorten efficient human life and must meet each problem according to its particular needs. The essence of democracy is the concept of rule by the people, who have a right to protect themselves against all forces that lead to illness or to death.

—Gaylord W. Anderson, 1952

Public health practitioners began to apply the field's basic science, epidemiology, to non-infectious diseases only in the middle of the twentieth century, after decades of using it to understand infectious diseases. <sup>411</sup> The new epidemiology, as the study of chronic diseases was called, started gradually in the 1910s and advanced rapidly in the 1940s and 1950s to include the statistical analysis of many non-infectious diseases and adverse health conditions such as heart disease and cancer. Until then, public health leaders had viewed these conditions as outside its scope of responsibility and had strongly resisted public and political pressure to pay attention to chronic diseases.

While public health policy had ignored chronic disease in general, it failed in particular to consider genetics as appropriate for attention. Public health experts paid scant notice to the obvious genetic components of the chronic diseases, even degenerative genetic conditions with clear and simple patterns of inheritance such as Huntington's

 $<sup>^{410}</sup>$  Gaylord W. Anderson, "Public Health—A Mandate from the People," *American Journal of Public Health* 42 (1952): 1367–73.

<sup>&</sup>lt;sup>411</sup> For a summary of the history of epidemiology, see Abraham M. Lilienfeld and David E. Lilienfeld, "Threads of Epidemiologic History," in *Foundations of Epidemiology, second edition* (New York, NY: Oxford University Press, 1980), 23–45; Dorothy Porter, *Health, Civilization, and the State: A History of Public Health from Ancient to Modern Times* (London, UK: Routledge, 1999).

disease. The idea that genetics was outside the realm of public health was officially about to change in Minnesota with the establishment of the Human Genetics Unit in 1960. For the first time in the United States, a health department would incorporate genetics into its programs and responsibilities.

# Genetics and Public Health: A Late Development

Reasons why the public health profession did not consider human genetics part of its purview prior to 1960 are not intuitive and need exploration. One possible reason may have been that public health leaders did not have sufficient knowledge about human inheritance to address genetic problems on a population basis. That explanation makes sense insofar as the field of human genetics itself was only emerging in the 1940s. Earlier geneticists, rooted in zoology and biology, had determined the principles and theories of genetics in lower orders of plants and animals, but not in complex organisms such as mammals. The "genetics of man," as the early geneticist, A. H. Sturtevant, called human genetics, represented seemingly insurmountable research challenges to scientists, given the genetic complexity of humans, their long lives, and their relatively small number of offspring. Lack of significant research, however, is not a sufficient explanation for why public health leaders ignored genetics before 1960. In fact, health departments had already assumed responsibility for the prevention of various other

<sup>&</sup>lt;sup>412</sup> Peter S. Harper, *A Short History of Medical Genetics* (New York, NY: Oxford University Press, 2008).

<sup>&</sup>lt;sup>413</sup> A. H. Sturtevant, "The Genetics of Man," *A History of Genetics*, with an introduction and afterword by E. B. Lewis, (Cold Spring Harbor, NY: Cold Spring Harbor Laboratory Press and Electronic Scholarly Publishing Project, 2000), 126–32, originally published in 1965 and 1967 by Harper and Row.

adverse health conditions in the areas of sanitation, maternal and child health, and chronic diseases.

Another explanation for why genetics came late to public health might be that the medical profession did not define genetic conditions as diseases until the 1950s.

Huntington's disease provides an example. As previously discussed, the framing of Huntington's as a medical condition by physicians followed a protracted course of understanding and acceptance that reflected their attitudes and beliefs about genetic diseases as untreatable. On one hand, physicians were slow to realize the potential application of human genetics in medicine, much less consider it as applicable for the prevention of specific genetic diseases in populations. On the other hand, that explanation makes sense only if one accepts the premise that public health was entirely shaped by medical concepts, an assertion not supported in other areas of public health practice.

Public health leaders consistently took positions in advance of and in opposition to the beliefs of physicians on many topics, a prime example being that many doctors considered chronic diseases inevitable and intractable while public health believed that surveillance could provide useful information for preventive interventions.

# The New Epidemiology: The Shift from Infectious to Chronic Diseases

Given that insufficient knowledge about human genetics and lack of an intellectual, medical framework for genetic diseases seems insufficient to account for the late embrace of genetics by public health, another explanation is that public health lacked the basic tools to study chronic disease on a population basis until the 1950s. For

<sup>&</sup>lt;sup>414</sup> See Alice Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease* (New Haven, CT: Yale University Press, 2008).

example, the prominent American epidemiologist, Milton Terris, recalled that his basic epidemiology course at The Johns Hopkins University's School of Hygiene in 1943 did not mention a single chronic disease. Similarly, the 1964 edition of a textbook on epidemiology first published in 1957 still focused almost exclusively on infectious diseases to illustrate epidemiological principles. The authors acknowledged, however, that between the first and second editions, "epidemiological thought has pervaded many branches of medicine widely." By contrast, an epidemiology textbook published in 1970 contained as many illustrations of epidemiological principles taken from chronic diseases as from diseases caused by infectious agents.

Terris and three other epidemiologists assumed the daunting assignment from the Pan–American Health Organization in 1988 of selecting important papers in the history of epidemiology for an anthology. In the section entitled "From the Old to the New Epidemiology," the four editors selected key papers that showed the advancement of epidemiology in the 1940s onward to include not only chronic diseases, but also social and cultural health issues such as violence, substance abuse, risky behavior, and mental illness. The editors postulated that the rise of the social medicine movement in the United Kingdom and the establishment of schools of public health in the United States were key factors in promoting epidemiology as a means to understand non-infectious disorders, a

<sup>&</sup>lt;sup>415</sup> The Challenge to Epidemiology: Issues and Selected Readings, eds. Carol Buck, Alvaro Llopis, Enrique Najera, and Milton Terris (Washington, DC: Pan American Health Organization, 1988), 93.

<sup>&</sup>lt;sup>416</sup> Ian Taylor and John Knowelden, *Principles of Epidemiology* (Boston, MA: Little, Brown, & Co., 1964, first published 1957).

<sup>&</sup>lt;sup>417</sup> Taylor and Knowelden, vi.

<sup>&</sup>lt;sup>418</sup> Brian MacMahon and Thomas F. Pugh, *Epidemiology: Principles and Methods* (Boston, MA: Little, Brown, & Co, 1970).

<sup>&</sup>lt;sup>419</sup> Buck, *The Challenge to Epidemiology*, 93.

States and the United Kingdom, this phenomenon was not as marked because in other developed countries the comprehensive universal health and insurance systems included preventive services and those nations did not perceive public health as a separate governmental responsibility. Terris dated the beginning of the Social Medicine movement in Britain to John Ryle becoming Oxford University's first Professor of Social Medicine in 1943. In the United States, the handful of existing schools of public health increased significantly during the 1940s, supplementing those at the University of Michigan, Harvard University, and the Johns Hopkins University. The newer schools included the School of Public Health at the University of Minnesota founded in 1944.

Epidemiologists and researchers first turned their attention to cancer in the 1920s and 1930s. Major Greenwood at the University of London included a discussion of cancer epidemiology in his 1935 textbook on epidemiology, but the content consisted entirely of descriptive epidemiology (who, what, where, when) of various cancers and

<sup>&</sup>lt;sup>420</sup> The Challenge to Epidemiology, 87–91.

<sup>&</sup>lt;sup>421</sup> The Challenge to Epidemiology, 86; Dorothy Porter, Social Medicine and Medical Sociology in the Twentieth Century (Amsterdam and Atlanta, GA: Rodopi, 1997).

<sup>&</sup>lt;sup>422</sup> George Rosen, *A History of Public Health* (New York, NY: MD Publications, 1958), 494; Elizabeth Fee, *Disease and Discovery: A History of the Johns Hopkins School of Hygiene and Public Health*, 1916–1939 (Baltimore, MD: Johns Hopkins University Press, 1987).

<sup>&</sup>lt;sup>423</sup> Harold S. Diehl, "Proposal for a School of Public Health," October 8, 1943, box 1, Papers of the School of Public Health, University of Minnesota Archives. Its purpose was to train public health physicians, nurses, and others, and to investigate community health problems. An appendix to the proposal contains a brief history of antecedents at the University of Minnesota, including the Department of Preventive Medicine in the Medical School that awarded master's degrees to physicians starting in 1922. The school became the first in the country to grant a master's degree in hospital administration (1948) and started the first Ph.D. program in epidemiology (1958) in the United States.

made no attempt to address underlying etiology. 424 In the United States, Congress passed the National Cancer Institute Act in 1937 to establish the federal government's commitment to cancer research and professional training. 425 The massive National Health Survey conducted in 1935–36, financially supported by the Works Progress Administration, provided data used to argue for health care reform and established the widespread popular belief that chronic diseases represented a public health problem of significant importance. 426 The beginning of large-scale research into cardiovascular disease epidemiology occurred in the Unites States in the late 1940s with the establishment of a dozen or more large community-based studies of the determinants and course of coronary artery disease. The best known of them, the Framingham study, began to collect data in 1949 on a cohort of more than five thousand Massachusetts adults. 427

#### Genetic Disease as a Public Concern

If the public health field needed epidemiology that extended beyond vital statistics and contagious disease to understand chronic diseases and their causes, including genetic conditions, it also required social, cultural, and political impetus for widespread, population-based application of this new knowledge. The establishment of

<sup>&</sup>lt;sup>424</sup> Major Greenwood, "On the Epidemiology of Cancer," first published in *Epidemics and Crowd Diseases; An Introduction to the Study of Epidemiology* (New York, NY: MacMillan Company, 1934), reprinted in *The Challenge to Epidemiology*, 112–21.

<sup>&</sup>lt;sup>425</sup> James T. Patterson, *The Dread Disease: Cancer and Modern American Culture* (Cambridge, MA: Harvard University Press, 1987); Victoria Angela Harden, *Inventing the NIH: Federal Biomedical Research Policy*, *1887–1937* (Baltimore, MD: Johns Hopkins University Press, 1986).

<sup>426</sup> George Weisz, "Epidemiology and Health Care Reform: The National Health Survey of 1935–1936," *American Journal of Public Health* 101, no. 3 (2011): 438–47.

<sup>&</sup>lt;sup>427</sup> Robert J. Goldberg, "Coronary Heart Disease," in *Prevention of Coronary Heart Disease*, eds. Ira S. Ockene and Judith K. Ockene (Boston, MA: Little, Brown & Company, 1992), 4–39; William G. Rothstein, *Public Health and the Risk Factor: A History of an Uneven Medical Revolution* (Rochester, NY: University of Rochester Press, 2003).

human genetics in public health purview was a political event as the people, through their elected officials, exercised their "right to protect themselves against all forces that lead to illness or to death." The Minnesota legislature authorized the state health department in 1959 to apply human genetic science and assume responsibility for protecting and preserving genetic health for the entire population. The work of the new Human Genetics Unit, as will be shown, depended on advocacy and social action as much as it did on science. For example, the charge for the health department to monitor birth defects and genetic abnormalities in the population was fueled by Cold War era public concern about the possibility of genetic damage from atomic fallout. 429

It remained to be seen in 1960 how public health, lacking any models or experience, would develop genetic preventive services on a statewide scale. Prevention and control of chronic diseases was the closest comparison, relying on disease registries and long-term epidemiological studies to monitor chronic adverse health conditions in the population. Chronic disease prevention also entailed promoting behavioral change at the personal level in conjunction with individual medical care, as would be the case for preventing or ameliorating many genetic diseases. Like chronic disease prevention, public health genetics operated with the understanding that the goal was not to eradicate genetic diseases, but it was intended to reduce incidence rates, minimize human suffering, and decrease the enormous financial cost to society. The Minnesota Human

<sup>428</sup> Gaylord Anderson, "Public Health—A Mandate."

Elisabeth Emerson, *Public Health Is People: A History of the Minnesota Department of Health from 1949 to 1999* (Minneapolis, MN: The Minnesota Department of Health, 2009), available only in electronic version from the Minnesota Department of Health upon request, 127. Fear of radiation led the Minnesota legislature in 1959 to create a radiological safety advisory committee to advise the health department on matters of radiation; the committee included Sheldon Reed, 111.

Genetics League had used cost associated with Huntington's disease and phenylketonuria to argue for public health genetics since the early 1950s.

The Minnesota Department of Health's Human Genetics Unit provided an important example of public health expanding its responsibilities into an area that had no direct precedent and no clear course of action. It offers an opportunity to consider the results of the implementation of new public health programs. But, before examining the development of the Human Genetics Unit, we need to understand public health principles and practice more broadly.

## The Organization of Public Health

Public health is a profession most often carried out by its practitioners in a governmental sphere such as a local, county, or state health department. The structure and organizations of health departments have changed over time to reflect needs to address particular problems recognized not only by scientific research but also the priorities of elected officials and perceptions of society.

In the mid-twentieth century, Minnesota's public health system at the local level was similar to that of most states. In an analysis of state and local public health capacity in the United States in 1945, Haven Emerson<sup>430</sup> listed six functions of local health departments:

1. Vital statistics (the recording, tabulation, interpretation, and publication of the essential facts of births, deaths, and reportable diseases)

<sup>430</sup> Charles Bolduan, "Haven Emerson: The Public Health Statesman," *American Journal of Public Health* 40 (1950): 1–4, a tribute on the occasion of Emerson's 75<sup>th</sup> birthday, delivered at the American Public Health Association annual meeting with response from Emerson.

- Control of communicable diseases, including tuberculosis, malaria, venereal diseases, and hookworm
- Environmental sanitation, including supervision of milk and milk products, food processing and public eating places, and maintenance of sanitary conditions of employment
- 4. Public health laboratory services
- Hygiene of maternity, infancy, and childhood, including supervision of the health of the school child
- 6. Health education of the general public so far as not covered by the functions of departments of education. 431

Although some of the categories such as maintaining vital statistics and providing health education for parents could just as well relate to chronic disease as general functions, this list of categories preceded the rise of the new epidemiology, the application of epidemiological methods to diseases and injuries other than those caused by infectious agents, and the specific incorporation of chronic disease prevention into public health.

Emerson cited the following statistics to characterize Minnesota's health status at the time. Per capita expenditures for local public health services in 1942 was fifteenth lowest among the states. However, the death rate was ninth lowest and the infant mortality rate was the second lowest, a third less than the national average. He cited Minnesota's "strong sense of home rule" as an unusual characteristic, with more than

 $<sup>^{431}</sup>$  Haven Emerson, Local Health Units for the Nation (New York, NY: Commonwealth Fund, 1945), 2.

2,700 counties, cities, villages, and townships "each of which is permitted to set up its own health organization." <sup>432</sup>

The functions of the state health department paralleled Haven's categories for local public health. In Minnesota, Albert J. Chesley, newly appointed secretary of the State Board of Health in 1921 had encountered a department that consisted of sanitation, vital record keeping, and infectious diseases. He gradually expanded the department into new areas of maternal and child health, public education, and industrial hygiene. 433 More than twenty-five years later, in 1947, Chesley presided over a thorough reorganization of the health department, abolishing the nine divisions that he had built since 1921 and creating a new organization of five sections: departmental administration, preventable diseases, medical laboratories, environmental sanitation, and special services. Chesley intended the revised structure to accommodate new programs in cancer, hotel inspection, mental health, water pollution, health in lumbering and industrial camps, and problems of Native Americans. 434 Some of these programs were not new, for example the Indian Nursing Service that started in 1923, but others such as mental health and cancer surveillance, and the reorganization offered a more comprehensive, coordinated structure for the health department. The change in the department's focus from infectious diseases to chronic, environmental, and social health problems not only mirrored the shift in the leading causes of deaths in Minnesota from tuberculosis, heart disease, and pneumonia in

<sup>432</sup> H. Emerson, Local Health Units, 154.

<sup>&</sup>lt;sup>433</sup> Philip D. Jordan, *The People's Health: A History of Public Health in Minnesota to 1948* (St. Paul, MN: Minnesota Historical Society, 1953), 178.

E. Emerson, *Public Health Is People*, 196.

1910 to heart disease, cancer, and strokes in 1949, but it also incorporated new epidemiological tools and research into the system.<sup>435</sup>

Perhaps because health concerns were often situated locally and in the states, the Federal government lagged behind the states in advances in public health. The United States Public Health Service, beginning in 1798 with hospitals for the care of sick seamen, focused almost exclusively on infectious diseases up until the 1960s. The service assumed its current name in 1912 with a Congressional mandate to control communicable diseases and maintain sanitation and safe water. Its corps of commissioned officers was started in 1889 primarily to investigate the etiology of infectious diseases. Early in the century, Joseph Goldberger (1879–1929), a commissioned officer of the Public Health Service, conducted research on pellagra, a disease widely thought to be an infectious disease. Goldberger, however, proved that it was caused by a nutritional deficiency of niacin. 436 His work, one of the earliest uses of epidemiology to study a non-infectious disease, was in that sense unintentional. 437 The Centers for Disease Control, the Public Health Service's prevention agency, was founded in 1942 as the Office of National Defense Malaria Control Activities during World War II. The name changed to the Communicable Disease Center (CDC) in 1946. 438

E. Emerson, *Public Health Is People*, 6.

<sup>&</sup>lt;sup>436</sup> Joseph Goldberger, "Considerations on Pellagra," *Public Health Reports* 29 (1914): 1683–6, reprinted in Buck, *Challenges in Epidemiology*, 99–102.

<sup>&</sup>lt;sup>437</sup> Joseph Goldberger and Alan M. Kraut, "The Etiology of Pellagra (1914) [with Commentary]" *Public Health Reports (1974)*, Historical Collection 1878–2005, 121 (2006): 76–9.

<sup>&</sup>lt;sup>438</sup> Elizabeth Etheridge, *Sentinel for Health: A History of the Centers for Disease Control* (Berkeley, CA: University of California Press, 1992).

The Public Health Service and its concentration of infectious disease control gradually transitioned towards a more comprehensive federal involvement in health and public health during the 1920s and 1930s, albeit without a national health program until the immediate pre-World War II era when the Federal Security Administration was created to unify and coordinate federal programs in health, education, and welfare. The first area of health addressed by the federal government outside of the Public Health Service was maternal and child health. Progressive era reformers such as Florence Kelley (1859–1932)<sup>439</sup>, a resident and member of the inner circle at Jane Addams's Hull House in Chicago, and Lillian Wald (1867–1940)<sup>440</sup>, mother of the field of public health nursing and founder of the Henry Street Settlement in New York, advocated for a federal Children's Bureau starting at the turn of the twentieth century. 441 They gained support from President Howard Taft in 1906, but it required six more years before Congress passed a law to establish the bureau. Kelley's colleague at Hull House, Julia Lathrop (1858–1932), was named director, and she used the pitifully small congressional appropriation of approximately \$26,000 a year to collect data about maternal and child health that enabled advocates to press for more substantial federal support for maternal and child health. 442 In 1921, Congress passed the Maternity and Infancy Act (Sheppard-Towner Act) that expanded the Children's Bureau, the first significant federal

<sup>&</sup>lt;sup>439</sup> Josephine Goldmark, *Impatient Crusader: Florence Kelley's Life Story* (Urbana, IL: The University of Illinois Press, 1953).

 $<sup>^{440}</sup>$  Robert Luther Duffus,  $\it Lillian~Wald,~Neighbor~and~Crusader~(New York, NY: The MacMillan Company, 1938).$ 

<sup>&</sup>lt;sup>441</sup> George Rosen, *A History of Public Health* (New York, NY: MD Publications, Inc, 1958), 351–64.

<sup>&</sup>lt;sup>442</sup> Jane Addams, *My Friend, Julia Lathrop* (New York, NY: The MacMillan Company, 1935).

appropriation for health and social welfare other than the Public Health Service, and they also allocated some services for veterans. In 1929, Congress refused to provide further support because of political pressure and critics in the medical establishment who saw the Bureau as encroaching on the practice of medicine. The Children's Bureau pre-dated the Sheppard-Towner Act in having received its own congressional appropriation in 1912 and lasted well after the Sheppard-Towner era ended, although in different forms. Support for maternal and child health re-emerged in 1935 on a large scale and the Children's Bureau was reconstituted under Title V of the Social Security Act. 444

The Public Health Service, part of the Department of Treasury, served as the *de facto* national health agency until 1939, when President Franklin Roosevelt proposed and Congress accepted the creation of the Federal Security Agency that incorporated the health, welfare, and educational services of the government, including the Children's Bureau. <sup>445</sup> In 1953, under President Dwight Eisenhower, it became a cabinet level department, the Department of Health, Education, and Welfare. <sup>446</sup>

#### **Genetics as a Public Health Concern**

By the 1950s, advances in human genetic science made it applicable for populations in accord with the older, traditional, categorical functions of public health such as maternal and child health and chronic disease prevention and control. Even so,

<sup>443</sup> Ellen Fitzpatrick, Endless Crusade: Women Social Scientists and Progressive Reform (New York, NY: Oxford University Press, 1990); Robin Muncy, Creating a Female Dominion in American Reform, 1890–1935 (New York, NY: Oxford University Press, 1991).

<sup>&</sup>lt;sup>444</sup> Rosen, A History of Public Health, 467

<sup>&</sup>lt;sup>445</sup> Kriste Lindenmeyer, "A Right to Childhood": The Children's Bureau 1912–1946 (Urbana, IL: University of Illinois Press, 1997).

<sup>446</sup> Rosen, A History of Public Health, 467.

lack of experience beyond chronic disease presented a challenge to public health practice in applying genetic knowledge to populations. For one example, genetic counseling made it possible to prevent certain hereditary diseases for individuals and families, but counseling services were not assuredly available to everyone equally in Minnesota because the need for such counseling services far exceeded the availability. In another example, registries for Huntington's disease provided a population-based assessment of individuals at risk for the disease, but they did not cover entire populations of states and did not address the policy question of who was ultimately responsible for providing individuals at risk with genetic counseling.

Registries for genetic diseases such as Huntington's disease were common long before their use by public health departments. In the late 1940s, geneticist James V. Neel attempted to compile registries of hereditary diseases in Michigan to be used for genetic research about inherited characteristics and spontaneous mutations. He wrote to Sheldon Reed that, "We are now getting two fair-sized 'population studies' under way, one involving retinoblastoma in the State of Michigan and financed by the American Cancer Society, and the other involving sickle cell anemia and financed by the United States Public Health Service." Neel also studied neurofibromatosis and multiple polyposis of the colon "to obtain a rounded picture of their impact on, and significance to, a given geographic area, namely, the state of Michigan." Huntington's disease, an autosomal dominant genetic defect, was the next disease that Neel intended to study using a statewide case registry. That goal proved more difficult because of its higher prevalence

<sup>&</sup>lt;sup>447</sup> James V. Neel to Sheldon C. Reed, reply to Neel from Reed, November 12, 1948, series 1, folder "Correspondence R-Ri," James V. Neel Papers, American Philosophical Society.

in the population than many of the rare, recessive genetic conditions, Huntington's hidden carriers, and severe social stigma for families and kindreds. 448

Maintaining disease registries of genetic conditions and using them both in counseling families and in estimating gene frequencies was, therefore, a well-known practice among human geneticists by the late 1940s, with a history originating with the relatively haphazard and incomplete trait files of the Eugenics Record Office that did not properly qualify as registries because of their lack of a population basis. 449 Genetic disease registries, however, were established and maintained mainly in university research centers such as those in Minnesota and Michigan, or in the private Carnegie Institution at Cold Spring Harbor, and usually lacked complete coverage for a state's entire population. Consequently, they had never yet reached the scope of size and inclusiveness to allow their use as the basis for public health programs and policy. The need for government to develop comprehensive, geographically and population-based genetic disease registries was clear to geneticists. The value of a Huntington's disease registry in particular, lacking in Minnesota, had been one of the strongest arguments used by advocates for Minnesota's 1959 public health genetics law to insure that every family affected by the disease would have sound advice based on science.

<sup>&</sup>lt;sup>448</sup> James V. Neel to Sheldon C. Reed, February 3, 1953, series 1, folder "Correspondence R-Ri," James V. Neel Papers, American Philosophical Society.

<sup>&</sup>lt;sup>449</sup> The papers of the Eugenics Record Office contain extensive trait files and related documents that make up most of the collection of 382 boxes (330.5 linear feet). The trait files (Series 1) are folders that contain published papers, pedigrees of particular families, reports from field workers, and other documentation of diseases or human traits that potentially had a genetic component from 1920 to 1944, Eugenics Record Office Records, American Philosophical Society.

### Potential Challenges as Public Health Genetics Took Shape

Since its founding in 1872 as the American Public Health Association, the field of public health and its practitioners had faced opposition and outright hostility from organized medicine which perceived it as encroaching on their turf. The proponents for creating a public health genetics unit in Minnesota's health department expected to face similar challenges in acceptance by the medical establishment. Surprisingly, the passage of the 1959 law to authorize the Human Genetics Unit to the Minnesota health department unexpectedly received little opposition from physicians.

Historically, physicians in Minnesota and elsewhere had fought public health every time it had expanded its attention and interventions into new areas. For example, Gaylord W. Anderson, the first dean of the University of Minnesota School of Public Health, had used his presidential address at the American Public Health Association's 80<sup>th</sup> annual meeting in 1952 to denounce organized medicine's resistance to the expansion of public health into chronic disease prevention. He was responding to a resolution adopted by the American Medical Association demanding that public health should be limited to the control of communicable disease and sanitation and should not be associated with anything resembling medical care or advice. <sup>450</sup> Providing a specific example of that resistance, Anderson argued that in the late nineteenth century public health officials in New York had needed to assure that infectious disease control measures were available to everyone in a timely manner, even though they met severe criticism from physicians who claimed that providing diphtheria anti-toxins and vaccine

<sup>&</sup>lt;sup>450</sup> W. L. Laurence, "Curbs Hit in Field of Public Health: Association President Scores an AMA Resolution to Restrict Its Activities," *New York Times*, October 21, 1952.

constituted personal medical care. Physicians at the time had vociferously denounced public health officials for overstepping their bounds and interfering in the practice of medicine. The policy of depending on private physicians to distribute anti-toxins and vaccines to everyone who needed them during outbreaks in New York City had been a proven failure, and public health had needed to intervene to control disease outbreaks and save lives.

Anderson pointed out similar criticism from physicians two decades later when public health enlarged its authority into the provision of preventive maternal and child health services under the Children's Bureau. Corresponding battles occurred a few years after that when public health reluctantly took greater responsibility for the prevention and control of some degenerative and metabolic diseases. For example, in 1926 the Massachusetts legislature directed its state health department to conduct screening for cancer, a program strongly opposed by organized medicine. The health department itself had supported the physicians' position, agreeing with them that cancer was a private and not a public health problem. The irate conservative Republican legislators and governor in Massachusetts overruled the health department and ordered it to establish clinics to diagnose and treat cancer "with or without cooperation on the part of local physicians."

<sup>&</sup>lt;sup>451</sup> Anderson, "Public health—A Mandate from the People."

<sup>&</sup>lt;sup>452</sup> Gaylord W. Anderson, "Landmarks of Communicable Disease Control—Past and Future," *Canadian Journal of Public Health* 61 (1970): 373–78.

<sup>&</sup>lt;sup>453</sup> Anderson, "Public health—A mandate from the people." For a discussion of cancer control as an activity of Minnesota's health department, see Philip D. Jordan, *The People's Health*, 427–430. In 1948 the Minnesota Department of Health, with support from the Minnesota Medical Association, created a cancer control program within its preventable diseases section.

Sheldon Reed applauded the 1959 law mandating the Human Genetics Unit but noted that the amount of attention and resources devoted to genetics was miniscule compared with other public health issues. In an example of his wry use of humor and understatement, Reed wrote, "The new law hardly elevates the gene to the same exalted status as *E. coli* but it is official recognition that man has genes and that something can be learned about them and that presumably the information can be utilized to advantage." He thus connected the responsibility of the state to identify and prevent genetic disease with its well-established legal power to control infectious diseases. By hearkening back to one of the first applications of state power to control disease, namely protection from contaminated food and water, Reed implied that defective human genes also needed the state's attention and that the government was obliged to take measures to protect and promote that aspect of the public's health.

Reed was certain that genetics was an appropriate concern of public health authorities, but he was not sure that legislators would agree. The advocates of the law to establish public health genetics in Minnesota, including health department officials themselves, had been pessimistic that legislators would agree to make human genetics a mandated public health activity. They were surprised when the law authorizing the Human Genetics Unit met no opposition in the legislative committee hearings and passed unanimously in both houses of the Minnesota Legislature.

<sup>454</sup> Sheldon C. Reed, Dight Institute *Bulletin No. 11*, (1959).

<sup>&</sup>lt;sup>455</sup> J. E. Bauman, *The Fundamentals of Public Health Law* (Washington, DC: United States Public Health Service, 1959), 1–10.

<sup>&</sup>lt;sup>456</sup> Letha L. Patterson, memorandum to Paul Christopherson, John S. Pearson, Sheldon Reed, V. Elving Anderson, and Jane McCarthy, February 24, 1959, box 3, folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.

The short time available to lobby and gather support for the Minnesota public health genetics bill was probably advantageous because the bill seemed to escape the notice of groups such as physicians and hospital officials who might have opposed it. The official journal of the Minnesota Medical Association finally took retrospective note of it in September of 1959 with a short item in its public health news column entitled, "Human genetics counseling program authorized." The author of the article focused primarily on genetic counseling services as the unit's main activity. The article highlighted other opportunities for physicians such as conducting research, providing consultation, sponsoring seminars, and enhancing teaching about genetics in the medical school. The tone of the note was not critical.

## **Organizing the Human Genetics Unit**

In August of 1959, Robert N. Barr, M.D., the executive secretary of the Minnesota Board of Health (precursor to the Minnesota Department of Health), acting under the new law, named the mandated nine-member advisory group for the as yet unorganized Human Genetics Unit. 458 Members of the Advisory Committee on Problems of Human Genetics included Ray Anderson and Sheldon Reed representing the Dight Institute. Also from the University of Minnesota were John A. Anderson, Chairman of Pediatrics; Robert Gorlin, Professor and Head of Oral Pathology in the Dental School; E. Adamson Hoebel, Professor and Chairman of Anthropology; and Frank Rarig, retired chairman of the Speech Department. Tague Chisholm, a community-based pediatrician,

96.

<sup>&</sup>lt;sup>457</sup> "Human Genetics Counseling Program Authorized," *Minnesota Medicine* 42 (1959): 1292 and

As Robert N. Barr to Sheldon Reed, August 18, 1959, box 3, folder "Board of Health," Dight Institute Papers, University of Minnesota Archives.

represented the Minnesota Medical Association. John Pearson, the psychologist who had helped gain passage of the authorizing legislation, held a research position at the Rochester State Hospital. The University of Minnesota's domination of the advisory committee perhaps reflected the status of human genetics as an academic field with scant interest from private medical practitioners.

The Advisory Committee on Problems of Human Genetics held its first meeting in April of 1960, staffed by A. M. Rosenfield, the physician in charge of the health department's maternal and child health section. Members elected Sheldon Reed as the chairman and John Pearson as vice chairman. The first item for discussion was a proposal from Reed outlining possible activities of the Human Genetics Unit. Members agreed that the unit should involve itself with education about genetics for doctors, child welfare agencies, and prospective parents, "make epidemiological surveys of traits and distribution of genes for particular diseases," and take responsibility for some of the genetic counseling services at the university that would permit the Dight Institute staff to concentrate on research instead. The second topic addressed the idea of requiring physicians to report certain "crippling and disabling conditions." The committee did not reach a conclusion about that issue. The last item was preliminary discussion of the job description for the human geneticist to be hired to run the unit that had been developed by Reed with input from advisory committee members and health department staff prior to the meeting. 460

<sup>&</sup>lt;sup>459</sup>Minutes, meeting of the Advisory Committee on Problems of Human Genetics, April 12, 1960, box 3,folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>460</sup> Minutes, Advisory Committee on Problems of Human Genetics, April 12, 1960.

The Advisory Committee on Problems of Human Genetics met again in May to approve the job specifications for the geneticist to be hired. Rosenfield reported that he had requested approval from the state civil service office to post the position at a recommend salary of \$9,000 "because specialists in human genetics are quite limited in number."461 The job description, approved by the advisory committee, stated that, "The employee would initiate, be responsible for, and direct the activities of the Human Genetics Unit of the State Board of Health" as authorized by law, and "would collect and interpret data relating to human hereditary diseases and pathological conditions." In addition, "he (or she) would speak to Medical societies and other groups desiring information about heredity in man," "write educational brochures on topics in human genetics for which there is public demand," "assist physicians throughout the state who wish to study families with specific genetic diseases," "counsel state agencies, child placing agencies, physicians and individuals regarding personal genetics problems," and "conduct research studies." The job description required not just sufficient human genetics knowledge with an advanced degree such as Ph.D. or M.D. and training in human genetics, but also the ability to communicate "at the popular level" and "maintain effective working relationships" with diverse organizations, colleagues, and state employees. Noting that the Human Genetics Unit was the first of its kind in the United States, the job description for the geneticist specified that the person hired had to be able to "improvise all procedures and practices."

<sup>&</sup>lt;sup>461</sup> A.B. Rosenfield, memorandum to members of Advisory Committee, May 6, 1959, box 3, folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.

#### The Human Geneticist Candidate: Lee E. Schacht

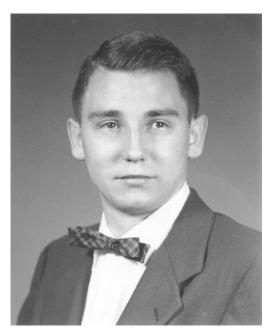
The Advisory Committee on Problems of Human Genetics disseminated inquiries to academic human genetics programs that numbered between ten and twenty, depending on the criteria to count them, to seek applicants for the job of public health geneticist. 462 Reed carried copies of the job description to the annual meeting of the American Society of Human Genetics in Memphis in late April of 1960 and found interest in the position from Lee E. Schacht, then at the University of Michigan's Heredity Clinic. Schacht subsequently sent Reed a letter of interest, his curriculum vitae, reprints of his publications, and references from his Ph.D. advisor at the University of North Carolina, Maurice Whittinghill; his fellowship director at Michigan, James Neel; and his colleague, H. Eldon Sutton, at Michigan. 463 Reed responded, "You sound like just what we want. We had not expected to find anyone with such good background for the work." Schacht visited Minneapolis to discuss the job with Reed, the advisory committee, and health department officials in June 1960, and was offered the job commencing on September 1, 1960 after he completed his work in Ann Arbor. 465

 $<sup>^{462}</sup>$  Lee R. Dice, "Heredity Clinics: Their Value For Public Service And For Research," *American Journal of Human Genetics* 4 (1952): 1–13.

<sup>&</sup>lt;sup>463</sup> Lee E. Schacht to Sheldon C. Reed, May 3, 1960, box 3, folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>464</sup> Sheldon C. Reed to Lee E. Schacht, May 6, 1960, box 3, folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.

<sup>&</sup>lt;sup>465</sup> Schacht to Reed, June 7, 1960, box 3, folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives.



*Figure* 8. Lee E. Schacht on his graduation from Dartmouth College, 1952. (Compliments of his niece, Nancy Leibfried)

Schacht earned a bachelor's of arts degree from Dartmouth College with an inter-disciplinary major in chemistry, zoology, and botany in 1952. He entered graduate school at the University of North Carolina's Department of Zoology and received a master's degree in January 1955 and a doctoral degree in 1957. Schacht's master's thesis was on genetic linkage in *Drosophila* and his doctoral dissertation on radiation effects on the genes of that organism. While at North Carolina, Schacht showed interest in public health by choosing parasitology as his minor, the closest equivalent to a master's degree in public health available there. In the summer of 1954, he attended a course in radiation

John Graham, pamphlet, "The Norma Berryhill Distinguished Lecture," University of North Carolina, series 1, folder "Correspondence Graf-Guo," James V. Neel Papers, American Philosophical Society. Whittinghill joined University of North Carolina's Zoology Department in 1942 and was the only geneticist on campus in 1946; he usually steered students to the Ph.D. programs at larger universities. Lee Schacht was the only student to complete a genetics Ph.D. at Chapel Hill before the genetics program was started.

<sup>&</sup>lt;sup>467</sup> Lee E. Schacht, "The Time Of X-Ray Induction Of Crossovers And Translocations in *Drosophila melanogaster* Males," *Genetics* 43 (1958): 5.

biology sponsored by Duke University and the Biology Division of the Oak Ridge National Laboratories.

Schacht moved to the University of Michigan Department of Human Genetics in the fall of 1956 as a National Institute of Health postdoctoral research fellow to study human genetics under James Neel. He attended all of the human genetics courses taught at Michigan. Schacht also joined a group of researchers studying pediatric diseases and correlations with blood types. In July of 1957, he resigned the fellowship to start an instructorship in the Department of Human Genetics as a genetic counselor at the University of Michigan Hospital.

Lee Schacht later sensed that James Neel was not "terribly impressed" with his decision to devote himself to public health genetics by accepting the job in Minnesota because it did not compare with the rigor and prestige of an academic position. In the long run, Schacht did not regret his decision, because the field of public health genetics was developing rapidly with funding from the federal government and the establishment

<sup>&</sup>lt;sup>468</sup> James V. Neel to Arno G. Motulsky, October 25, 1990, series 1, folder "Correspondence Mo-Mu," James Neel Papers, American Philosophical Society. The letter clarified that contrary to statements in Barbara J. Culliton, "Mapping Terra Incognita (Humani Corporis)," *Science* 250 (October 12, 1990): 211, the first free-standing Department of Human Genetics in a medical school in the United States came into existence in 1956 at the University of Michigan. Other schools only had sections of human genetics within their departments of internal medicine (University of Washington and Johns Hopkins University.

<sup>&</sup>lt;sup>469</sup> Lee E. Schacht and H. Gershowitz, "Correlation Between Potentially Fatal Disease In Children and Blood Types," *Proceedings of the ABIS* (August 1959); H. Gershowitz and Lee E. Schacht, "The Relation of Blood Groups to Leukemia, Nephrosis-nephritis, Congenital Health Defects, and Rheumatic Fever: Sib Analysis," *Annual Proceedings of the American Society of Human Genetics*, (May 1960); Lee E. Schacht and H. Gershowitz, "Frequency of Extra-marital Children as Determined by Blood Groups," *Proceedings of the Second International Conference on Human Genetics*, (September 1961).

<sup>&</sup>lt;sup>470</sup> Lee Schacht to Sheldon Reed, May 3, 1960, box 3, folder "Board of Health Bill," Dight Institute Papers, University of Minnesota Archives, cover letter for Schacht's *curriculum vitae*. At the time of his departure from Michigan, Schacht was a member of the American Society of Human Genetics, the Genetics Society of America, American Association for the Advancement of Science, American Institute of Biological Sciences, and Sigma Xi, the scientific research society.

of public health genetics programs in most state health departments within five years of Schacht starting the program in Minnesota.<sup>471</sup>

Schacht's impression that Neel did not perceive the public health job favorably was confirmed in Neel's letter of recommendation. Neel referred to the position at the health department as being a "niche" suitable for a geneticist such as Schacht who was more interested in applied human genetics rather than in research and academia. Neel not only demonstrated disdain for applied work in genetics, but he seemed to rate Schacht's potential as a human geneticist as low because of his lack of "curiosity." Neel had his own assessment of public health priorities in general, writing in later years to historian Diane Paul that he had always thought that public health would be better served by providing adequate amounts of nutritious food than by screening newborns for rare genetic diseases requiring dietary therapy:

The implication is that in the context of limited resources, it would be far more important for the genetic well being of a population to concentrate on improving the IQ of many people by dietary manipulation than improving the genetic well being of a few people with rare genetic diseases by the expenditure of the same amount of research funding.<sup>473</sup>

He objected to using public resources to address a relatively small number of cases of genetic disorders rather than concentrate on more basic problems for larger numbers of individuals or population as a whole. Views similar to Neel's did not come up during the debate about legislation for the Human Genetics Unit in Minnesota, perhaps reflecting

<sup>471</sup> Interview with Lee E. Schacht.

<sup>&</sup>lt;sup>472</sup> James V. Neel to Sheldon C. Reed, June 13, 1960, series I, box 4, folder "Correspondence R-Ri," James V. Neel Papers, American Philosophical Society.

<sup>&</sup>lt;sup>473</sup> James V. Neel to Diane B. Paul, August 13, 1991, series I, folder "Correspondence Pa-Pi," James V. Neel Papers, American Philosophical Society.

Neel's orientation as a practicing physician and his passion for population-based genetics as a research endeavor rather than applied public health.<sup>474</sup>

# The Establishment of Public Health Genetics in Minnesota

Public health genetics in Minnesota began with the creation of the Human Genetics Unit at the state health department in September of 1960 by Lee Schacht. As Sheldon Reed had noted, Schacht was superbly prepared to be the first geneticist in a public health department in the United States. He enjoyed the benefit of rapidly developing knowledge about human genetics, a supportive academic network at the University of Minnesota, and strong backing for human genetics from community advocates. On the other hand, he faced the challenge of inventing the practice of public health genetics each day on the job.

The Human Genetics Unit was placed in the Division of Special Services, headed by A. B. Rosenfield, created in 1956 when the number of divisions in the health department increased from five to seven. For the first nine years, the Human Genetics Unit and the other special services were physically located on the University of Minnesota's St. Paul campus in the Student Health Service Building, along with the Division of Local Health Administration, the health mobilization coordinator, and units for local health services, special services, maternal and child health, nutrition, family

<sup>&</sup>lt;sup>474</sup> James V. Neel, *Physician to the Gene Pool: Genetic Lessons and Other Stories* (New York, NY: Wiley & Sons, 1994).

<sup>&</sup>lt;sup>475</sup> Interview with Lee E. Schacht.

<sup>&</sup>lt;sup>476</sup> E. Emerson, *Public Health Is People*, 125. The other divisions were: environmental sanitation, local health services, administration, disease prevention and control, and medical laboratories. The two new divisions added in 1956 were special services and hospital services.

education, and dental health. 477 Other sections of the health department were housed elsewhere, including the State Office Building in St. Paul and the five-story building on the Minneapolis campus that had been built for the health department with assistance from a Works Progress Administration grant in 1938. The building in Minneapolis was not adequate in size nor was it safe for employees handling infectious materials. After many unsuccessful tries, health department officials succeeded in 1967 to obtain funds to construct a new, modern home for the health department. In 1969, the Human Genetics Unit, along with all employees and units of the health department, moved into the new six-story building at 717 Delaware Street, SE, just off the University of Minnesota medical school campus. This marked the first time in its history that all employees and divisions of the state health department were together under one roof. The Human Genetics Unit was an integral program within the overall structure of the health department and enjoyed access to its overall administration and laboratory services.

## **Advising the Work of the Human Genetics Unit**

The Advisory Committee on Problems of Human Genetics met on September 23, 1960, to continue discussion of the Human Genetics Unit and Schacht joined its members. The first topic on the agenda focused on genetic disease registries. Schacht noted that registries had to be practical, that data needed to be easily available, that the

<sup>&</sup>lt;sup>477</sup> Minnesota Department of Health, *Minnesota's Health*, Vol. 20, No. 6, June–July 1966, p. 4.

<sup>&</sup>lt;sup>478</sup> Minnesota Department of Health, notes on building history distributed at open house for new building at 717 Delaware Street in 1969.

<sup>&</sup>lt;sup>479</sup> E. Emerson, *Public Health Is People*, 183.

<sup>&</sup>lt;sup>480</sup> E. Emerson, *Public Health Is People*, 174. There were 340 employees in 1969.

<sup>&</sup>lt;sup>481</sup> Minutes, Advisory Committee on Problems of Human Genetics, September 23, 1960, box 3, folder "Board of Health," Dight Institute Papers, University of Minnesota Archives.

collection of the information not too time-consuming, and that modern data management systems using computers could be employed. Committee members suggested registries for congenital diseases and phenylketonuria (PKU), cross-indexed for diagnosis and identification among newly admitted patients and established inmates in the state hospitals. The second part of the meeting addressed methods to make genetic counseling available to state institutions (state hospitals, adoption agencies, and welfare offices), physicians, and community hospitals as resources permitted. Strategies to use records of the genetic counseling for research were also discussed. Schacht reported that he had already worked with the Department of Public Welfare to obtain access to "files at the state hospitals for use in counseling." Advisory committee members specified that genetic counseling in state agencies and institutions would serve to enable those agencies to understand the implications of this material. This emphasis on state hospitals and inmates seems to have had parallels to earlier eugenic approaches to implementing genetic interventions, perhaps because wards of the state had no "right" to privacy.

At a 1968 advisory committee meeting, Schacht asked its members for guidance "when questions arise concerning the genetic implications of sterilization and abortion." At the time, Minnesota, like twenty-eight other states, allowed abortion only to preserve the life of the mother, the situation that existed until 1973, when the US Supreme Court handed down *Roe v. Wade* decision. The unit's policy was to follow the same procedures used in genetic counseling, to provide complete information about options but

 $<sup>^{482}</sup>$  Minutes, Advisory Committee on Problems of Human Genetics, September 23,1960.

<sup>&</sup>lt;sup>483</sup> Barbara Hinkson Craig and David M. O'Brien, *Abortion and American Politics* (Chatham, NJ: Chatham House, 1993). Prior to 1973, the option of legal abortion was available in four states and the District of Columbia and allowed in thirteen states to protect the woman's physical and mental health.

leave all decisions about actions "to the individuals or couples and their physician." The committee recommended that state staff continue this policy. Presumably, the option of abortion for a life-threatening defect in the fetus or child and not the life of the mother existed only if the woman traveled to a jurisdiction that allowed pregnancy to be terminated on those grounds.

#### **Growth of the Human Genetics Unit**

The Human Genetics Unit faced a threat after just one year, in 1961, when the Governor Elmer Anderson proposed to eliminate it from the state budget as an austerity measure. The Advisory Committee on Problems of Human Genetics met jointly with the Minnesota Human Genetics League on February 20, 1961 to form a strategy to counter the governor's proposal. Although records of the interaction between the Advisory Committee and the League did not survive or reasons why the League was involved instead of state agencies or medical school departments, together they apparently fended off the threat.

Starting in July 1963, two years after the Guthrie blood test for phenylketonuria was invented, the health department's laboratory offered PKU screening of newborns on a voluntary basis. In Massachusetts in 1962, a pilot program using the test to screen newborns for PKU had resulted in maternity hospitals to screen nearly all babies for the

<sup>&</sup>lt;sup>484</sup> Minutes, Advisory Committee on Problems of Human Genetics, February 20, 1961, box 3, folder "Board of Health," Dight Institute Papers, University of Minnesota Archives.

For the adoption of legislation concerning mandatory PKU testing, see M. Susan Lindee, "Babies' Blood: Phenylketonuria and the Rise of Public Health Genetics," in *Moments of Truth in Genetic Medicine* (Baltimore, MD: The Johns Hopkins University Press, 2005), 45–48.

condition. 486 With strong support from PKU clinicians, advocates for the mentally retarded, and parents of affected children, PKU testing caught on quickly across the United States. In 1965, the Minnesota legislature required screening for PKU and other inborn errors of metabolism. 487 The mandate for hospitals to send blood from all newborns for PKU testing encountered limited resistance at first, but as had happened in Massachusetts, it abated. A few physicians and hospitals opposed the law because of perceived cost, logistics, and objections to state interference in private affairs, but within two years, nearly every hospital in the state was in compliance with sending blood to Minneapolis for newborn screening. 488 Lee Schacht was involved in getting the hospitals to cooperate and answering questions from physicians. 489 The Human Genetics Unit set up a registry for the affected PKU children and their families and assisted them in following the difficult dietary treatment. 490 The number of live births in Minnesota fluctuated in the 1950s and 1960s from a high of 87,523 in 1960 to a low of 56,483 in 1975; in most other years following 1960, the number was in the range of 65,000 to 70,000. 491 Given the rate of approximately one case of PKU in 10,000 births, the

<sup>&</sup>lt;sup>486</sup> Diane B. Paul, "PKU Screening: Competing Agendas, Converging Stories," in *The Politics of Heredity: Essays on Eugenics, Biomedicine, and the Nature–Nurture Debate* (Albany, NY: The State University of New York Press, 1998), 173–86.

<sup>&</sup>lt;sup>487</sup> Chapter 205, amending Minnesota Statutes, Chapter 144, 1961.

<sup>&</sup>lt;sup>488</sup> Interview with Lee E. Schacht.

<sup>&</sup>lt;sup>489</sup> Interview with Lee E. Schacht.

<sup>&</sup>lt;sup>490</sup> Interview with Lee E. Schacht.

Newsletter 258 of the Minnesota Legislative Commission on the Economic Status of Women, 4, April–May 2002. http://www.commissions.leg.state.mn.us/oesw/newsletters/april\_may02.pdf. Accessed February 2, 2011.

department identified and managed three to six cases a year. PKU clinicians, the National Association for Retarded Children, and supporters at the Children's Bureau dominated the argument about the cost of screening compared with the economics of caring for affected individuals in favor of screening. 493

On April 7, 1964, Schacht reported to the advisory committee that the Human Genetics Unit was thriving. 494 The previous year, he had counseled thirty-two cases; served more than one hundred families with congenital anomalies affecting the mouth and lips through genetic counseling at dental—facial clinics, fielded seventeen physician inquiries about genetic disease, and participated in weekly genetics rounds at the Medical School in the departments of internal medicine and pediatrics. He had given lectures in the community and at the School of Public Health and published research supported by the Rockefeller Institute on genetic variants in the serum proteins among residents of the Red Lake Indian reservation. 495 Two students from the School of Public Health had helped him modify and expand the Confidential Medical Report used to collect data on congenital malformations on the birth certificate, and they had compared its reliability with hospital records, a project that attracted national attention. The additional data collected in the expanded report included "congenital malformations, birth injuries,"

<sup>&</sup>lt;sup>492</sup> John B. Bartram, "Mental Retardation," in *Textbook of Pediatrics*, 9<sup>th</sup> edition, eds. Waldo E. Nelson, Victor C. Vaughn, III, and R. James McKay (Philadelphia, PA: W. B. Saunders Company, 1969), 113–20.

<sup>&</sup>lt;sup>493</sup> Paul, "PKU Screening," 174.

<sup>&</sup>lt;sup>494</sup> Minutes, Advisory Committee on Problems of Human Genetics, April 7, 1964.

<sup>&</sup>lt;sup>495</sup> H. R. Cleve, R. L. Kirk, W. C. Parker, A. G. Beam, A.G., L. E. Schacht, H. Kleinman, W. R. Norsfell, "Two Genetic Variants Of The Group-Specific Component Of Human Serum: Gc Chippewa And Gc Aborigine," *The American Journal of Human Genetics* 15(1963): 368–79. The role of Schacht and the Minnesota Department of Health was to organize the collection of blood samples on the Red Lake Reservation and interview subjects about their familial connections.

erythroblastosis, complications of labor and delivery, and multiple births."<sup>496</sup> A joint effort with the Faribault State School and Hospital followed families of PKU children with disease-related developmental disabilities residing in the state school to identify the carrier status of relatives. The Unit worked with Alice Chenoweth at the federal Children's Bureau to prepare a paper on public health genetic counseling for the annual national meeting of state health officers.<sup>497</sup>

### **National Symposia on Public Health Genetics**

In the early 1960s, the federal government showed strong interest in publicizing new knowledge about population genetics and linking it to public health's increasing concern with chronic disease surveillance and the "new" epidemiology. In 1963, the Division of Chronic Diseases of the US Public Health Service cosponsored with the University of Michigan Schools of Medicine and Public Health a symposium about the relationship of epidemiology, genetics, and chronic diseases. The presenters in Ann Arbor covered basic research principles in population genetics and epidemiology. They detailed specific examples of genetic susceptibility to diseases such as erythroblastosis fetalis based on ABO blood groups and described epidemiological aspects of chronic diseases such as diabetes, coronary artery disease, and rheumatoid arthritis. Thomas Francis, Jr., M.D., the chairman of the Department of Epidemiology in the School of Public Health and Professor of Epidemiology in the Department of Pediatrics and

 $<sup>^{\</sup>rm 496}$  Minutes, Advisory Committee on Problems of Human Genetics, April 7, 1964.

<sup>&</sup>lt;sup>497</sup> Minutes, Advisory Committee on Problems of Human Genetics, April 7, 1964.

<sup>&</sup>lt;sup>498</sup> James V. Neel, Margery W. Shaw, and William J. Schull, eds. *Genetics and the Epidemiology of Chronic Diseases* (Washington DC: US Department of Health, Education, and Welfare, Public Health Service, Publication No. 1163, 1965), 395.

Communicable Diseases at Michigan, presented the keynote address in which he considered the complex roles of both genetics and environment in the expression of chronic disease in populations."<sup>499</sup> Franz J. Kallmann made the final presentation of the symposium, about genetic counseling and noted that most physicians oriented toward therapies for individuals thought that genetic counseling did not represent a medical cure for an individual but belonged in preventive medicine and public health. <sup>500</sup> Yet, others would argue, genetic counseling as it occurred on a day-to-day basis constituted a distinct medical service that required individuals to make decisions about what to do even though it is preventive rather than curative. <sup>501</sup>

Lee Schacht served as a member of the Ann Arbor symposium's planning committee. Denote the Solution of the Experience, he organized two large symposia on public health genetics in Minneapolis with a different federal agency, the Children's Bureau, and with the University of Minnesota School of Public Health. The first, "Human Genetics in Public Health" in 1964, drew participants from health departments and universities in thirty-four states and Canadian provinces. Alice D. Chenoweth, the Children's Bureau Chief, gave the keynote address, noting that Minnesota was a fitting venue for the "first conference on genetics as related to maternal and child health and crippled children's programs" because it was the earliest state health department to have

Thomas Francis, Jr., "Genetics and Epidemiology," in *Genetics and the Epidemiology of Chronic Diseases*, 1–6.

<sup>&</sup>lt;sup>500</sup> Franz J. Kallmann, "Some Aspects of Genetic Counseling," in *Genetics and the Epidemiology of Chronic Diseases*, 385–395.

<sup>&</sup>lt;sup>501</sup> Ruth Schwartz Cowan, *Heredity and Hope*.

<sup>&</sup>lt;sup>502</sup> Neel, Shaw, Shull, Genetics and the Epidemiology of Chronic Diseases, iv.

<sup>&</sup>lt;sup>503</sup> Alice D. Chenoweth, "Foreword," in *Human Genetics in Public Health*, (Minneapolis, MN: Minnesota Department of Health, 1964), v–vii.

hired a full-time geneticist. She attributed the existence of Minnesota's Human Genetics Unit to Sheldon Reed, saying that he had convinced the Minnesota Legislature "of the importance of genetics to public health." As to why public health genetics was important, Chenoweth cited the statistic that the estimated 120,000 children in the United States with congenital hereditary malformations comprised nearly 30 percent of those receiving services from state crippled children's welfare programs. As evidence of the federal government's commitment to public health genetics, Chenoweth highlighted the Children's Bureau support for field trials of the Guthrie test for phenylketonuria (PKU) on more than 400,000 newborns in 1962 and 1963, technology that paved the way for widespread testing of newborns in 1964 by state health departments, including Minnesota's Department of Health. 504

Lee Schacht opened the conference with a speech about the philosophical relationship of genetics to public health. <sup>505</sup> He argued that the traditional tools of public health such as epidemiology, studies of disease clusters, and population statistical methods enabled scientists to study genetic aspects of disease effectively. Second, public health's focus on environmental health contributed to the identification of possible damage to human genes from radiation and pollutants. Finally, Schacht emphasized that genetics related directly to the practice of traditional public health professions such as public health nursing, public health education, and medical social work in that genetic diseases appear with great frequency among the case loads of public health workers

<sup>504</sup> For a discussion of the Children's Bureau's field trials of the Guthrie test, see Susan Lindee, *Moments of Truth*, 36–45.

<sup>&</sup>lt;sup>505</sup> Lee E. Schacht, "The Applications Of Genetic Knowledge To Various Public Health Disciplines," in *Human Genetics in Public Health*, 1–8.

providing care to individuals in communities. In all these theoretical considerations, the Human Genetics Unit at the Minnesota Department of Health measured up with corresponding programs and activities.

James R. Miller, of the University of British Columbia Medical School, discussed the relationship of genetics to public health research and programming. <sup>506</sup> He suggested strategies for public health genetics units at the state or provincial level. First, the magnitude of the load of genetically determined disease in a community could be ascertained through statistics. Second, disease registries could be maintained and be linked to other vital statistics data. Third, registries could be examined to identify pockets or clusters of disease in geographic or demographic patterns possibly associated with environmental factors. Fourth, public health programs could employ or promote preventive measures for genetic diseases through genetic counseling. Fifth, public health might minimize the impact of some genetic diseases on the individual, family, and society through treatment made possible by early detection.

Other papers discussed educational programs in public health genetics in schools of public health. Bernice Cohen, from the Johns Hopkins University, argued for a comprehensive genetics curriculum for all public health students and stressed that basic training in human genetics cannot be satisfied by pre-requisite courses before admission or by piecemeal information in existing courses within a school of public health. She emphasized her belief that all students in master's or doctoral level public health

<sup>&</sup>lt;sup>506</sup> James R. Miller, "Human Genetics in Public Health Research and Programming," *Human Genetics in Public Health*, 21–33.

<sup>&</sup>lt;sup>507</sup> Bernice H. Cohen, "Academic Programs in Human Genetics Now Being Presented at Schools of Public Health: The Johns Hopkins Program, in *Genetics in Public Health*, 51–66.

programs should receive instruction in genetics "because of the importance of genetics in the comprehension of the etiology and natural history of diseases, as well as the evaluation of specific applications in public health programs." Ira Gabrielson, from Yale University, recommended that genetics be required in the core curriculum for all public health students and that more electives be available for advanced study of applied public health genetics. For Helen M. Wallace and Victor Eisner, from The University of California, Berkeley, described the role of genetics in the curriculum of the maternal and child program at their school of public health. These presentations, taken together, indicate that public health academics were not ignoring genetics or ceding the instruction of their students in genetics to their affiliated medical schools or biology departments, but genuinely saw genetics as an integral and important component of public health.

Three presentations at the symposium described genetic programs in state agencies and institutions. The representative of the Connecticut State Department of Health emphasized chronic disease research such as the Connecticut Tumor Registry as a model for disease registries for genetic conditions. In that state, the department's geneticist did not "see or counsel the individuals personally" because Connecticut's statute prohibiting birth control allowed no legal means to prevent pregnancy through contraception. <sup>511</sup> Instead, Connecticut's health department maintained a phenylketonuria

 $<sup>^{508}</sup>$  Cohen, "Academic Programs in Human Genetics," 64.

<sup>&</sup>lt;sup>509</sup> Ira Wilson Gabrielson, "The Teaching of Human Genetics in the Yale University Department of Epidemiology and Public Health," in *Human Genetics in Public Health*. 67–72.

<sup>&</sup>lt;sup>510</sup> Helen M. Wallace and Victor Eisner, "Genetics in a Maternal and Child Health Training Program," in *Human Genetics in Public Health*. Minneapolis, MN: Minnesota Department of Health, 73–81.

<sup>&</sup>lt;sup>511</sup> N. C. Myrianthopoulos, Review of *Human Genetics in Public Health*," published by the Minnesota Department of Health, *American Journal of Human Genetics* 18 (September 1966): 505–6. The

registry and offered a support system for families to enhance adherence to the dietary treatment. The Connecticut example of a ban on birth control limiting the options of public health highlighted the political identification of health departments as governmental agencies. Similar policy questions occurred in Minnesota and elsewhere a few years later regarding constraints on genetic counseling provided by the state in regard to abortion.

Arthur Falek described the history and organization of the Department of Medical Genetics at the New York State Psychiatric Institute at Columbia University, founded in 1936 by psychiatrist Franz J. Kallmann. The department, a unit of the New York State Department of Mental Hygiene, maintained academic and governmental connections that provided researchers with access to patients at New York's state hospitals. Among the department's primary achievements were studies of identical twins to assess the genetics of schizophrenia. The department established a cytogenetics division in 1962 and developed a capacity for conducting genetic counseling associated with the laboratory. <sup>513</sup>

Lee Schacht made the final presentation of the conference on the topic of human genetics in public agencies, and described the program in Minnesota.<sup>514</sup> Unlike his theoretical opening remarks, his talk about the human genetics unit focused on service: genetic counseling; crippled children's services; laboratory screening and genetic testing;

review pointed out the irony that birth control was illegal in Connecticut while its health department employed a geneticist to handle genetic counseling cases. In 1965, the Supreme Court of the United States struck down Connecticut's law prohibiting the prescription of contraceptives to married couples.

<sup>&</sup>lt;sup>512</sup> Merton S. Honeyman, "The Genetics Program of the Connecticut State Health Department," in *Human Genetics in Public Health*, 83–7.

<sup>&</sup>lt;sup>513</sup> Arthur Falek, "Research, Training, and Counseling in Human Genetics," in *Human Genetics in Public Health*, 89–96.

<sup>&</sup>lt;sup>514</sup> Lee Schacht, "The Human Genetics Unit in the Minnesota State Department of Health," in *Human Genetics in Public Health*, 98–104.

and research on rare diseases and gene frequencies. He also mentioned the production of "a steady but constant stream of written material" about genetics and seminars on genetics for physicians, nurses, and social workers in the state.

The second Minneapolis conference, "Nutrition and the Inherited Diseases of Man as Related to Public Health," was held in 1966. The conference, also arranged by Lee Schacht with support from the federal Children's Bureau, gave nutritionists and public health geneticists the opportunity to explore areas in which their fields overlapped. Nutritionists from thirty-two states and several federal agencies convened for four days to hear a variety of presentations. About half of the presentations covered the dietary management of phenylketonuria infants identified during public health newborn genetic screening. Other speakers discussed the roles of genetics and nutrition in chronic metabolic diseases such as diabetes, coronary heart disease, and cystic fibrosis. 515

In her 1964 opening remarks, Alice Chenoweth paid tribute to Sheldon Reed for "convincing the Minnesota Legislature of the importance of genetics to public health." Federal officials as well as public health officials and human geneticists recognized Minnesota as leading the way. That the Children's Bureau supported the symposia in Minneapolis and went as far as Chenoweth did in recognizing Minnesota's contribution to public health genetics and that public health officials and researches from a majority of states attended these symposia must have gratified and pleased Sheldon Reed and Lee Schacht.

<sup>&</sup>lt;sup>515</sup> Nutrition and the Inherited Diseases of Man as Related to Public Health, (Minneapolis, MN: Minnesota Department of Health, 1966).

#### The Middle Years of the Human Genetics Unit

By the mid-1960s the Human Genetics Unit had expanded its activities into new areas while maintaining the ones that already existed. In 1966, the unit conducted genetic counseling for fifty-four individuals, agencies, and patient organizations, delivered ten lectures on genetics and public health for the University of Minnesota School of Public Health, completed the project with PKU patients at Faribault, studied hard of hearing children in one Minnesota county, and offered education for staff and students at two Child Development Centers in Minnesota.

Schacht received requests for information about organizing human genetics units from around the country. He provided consultation to the Contra Costa County Health Department and the California Department of Health genetics unit in 1966 and conducted an evaluation of genetic services in Region VI (upper Mid-West) for the Children's Bureau. <sup>516</sup> In reply to a 1967 inquiry from California's Department of Health about public health agencies in regard to human heredity diseases, Schacht wrote:

While there are obvious areas in which state or local health agencies might operate, that is screening programs, cytogenetics laboratories, etc., these alone do not constitute a genetics program. It is my feeling that the responsibility of the public health agencies and officials is to provide physicians, local health agencies, and families with correct and proper services in the total area of human genetics, including adequate and intelligent counseling for all people involved in the care and treatment of the patient. 517

<sup>&</sup>lt;sup>516</sup> Minutes, Advisory Committee on Problems of Human Genetics, June 28, 1966.

<sup>&</sup>lt;sup>517</sup> Lee E. Schacht to Robert W. Day, April 5, 1967, box 3, folder "Board of Health," Dight Institute Papers, University of Minnesota Archives.

By 1968, the Human Genetics Unit had further expanded its size and responsibilities. <sup>518</sup> The genetic counseling workload required that an additional geneticist, Malcolm Jenkins, be hired. A Ph.D. candidate in human genetics was also hired to supervise the cytogenetics lab. The Human Genetics Unit remained administratively under the health department's Section of Maternal and Child Health in the Division of Special Services, with three staff members including Schacht and Jenkins. The cytogenetics and newborn screening laboratories were administratively housed in a different part of the organization, the Laboratory Division. The placement of the Human Genetics Unit and the genetic laboratories in separate divisions bothered the advisory committee, who wanted them combined, but that recommendation was not followed.

The Human Genetics Unit was at its zenith in the early 1970s. A program performance report in 1974 indicated that 155 patients and families had received genetic counseling that year. The two geneticists had provided consultation to 283 health professionals that year. At the request of Minnesota physicians, the laboratory had run 173 chromosomal karyotype evaluations, 191 metabolic studies, and 45 biochemical special procedures at a cost of \$40 for the chromosomal test and \$10 for the routine biochemical tests. The staff had conducted eighteen presentations for 371 health professionals, taught a one-quarter course at the University of Minnesota School of Public Health, provided consultation to the Medical School at the University of Minnesota–Duluth, and participated in two television and two radio programs with

 $<sup>^{518}</sup>$  Minutes, Advisory Committee on Problems of Human Genetics, May 28, 1968.

<sup>&</sup>lt;sup>519</sup> Performance report, Human Genetics Unit, 1974, box 1, folder "Chronological Correspondence, Lee E. Schacht, 1974," Papers of the Minnesota Department of Health, Minnesota Historical Society.

statewide reach. The geneticists also had provided seven educational programs to groups with hereditary problems including the Committee to Combat Huntington's Disease, National Ataxia Foundation, and the Minnesota Muscular Dystrophy Foundation, the first two groups requesting and receiving help directly from the Human Genetics Unit's geneticists in their periodic diagnostic and treatment clinics. <sup>520</sup> In 1976, the Human Genetics Unit began to test the blood of the newborns for galactosemia and hypothyroidism (cretinism). <sup>521</sup> In all these activities, the health department in Minnesota offered services similar to those in most other states.

Responsibilities of the Human Genetics Unit grew to include activities that were only tangentially related to genetics. For example, Lee Schacht was given supervision over another activity within the maternal and child section called Health Resources for the Handicapped. This specially funded program supplemented the existing network of state-supported clinics and programs for crippled children that had existed for decades. A staff of five worked on "the identification and treatment of children who are mentally retarded or otherwise handicapped" to help them with health, social, and educational needs. The staff in the central office functioned in conjunction with two regional child development centers, one in Fergus Falls and the other in Owatonna, that saw children up to age 21 years for diagnosis and referral, including pediatric, psychological, nursing, and social service evaluations. Staff at the centers, assisted by the five people at the health department, devised a treatment plan for each child, discussed the plan with parents, and

<sup>&</sup>lt;sup>520</sup> Performance Report, 1974.

<sup>&</sup>lt;sup>521</sup> Lee Schacht to Tom Mabry, Memorandum, December 29, 1976, box 2, folder "Chronological Correspondence 1975–1976,Lee E. Schacht, October 1975 to December 1976," Papers of the Minnesota Department of Health, Minnesota Historical Society. The cost of the hypothyroidism test was \$1.00 per test for each of the 55,000 samples.

made referrals to local services, including Crippled Children Services for physical conditions, to implement it. Staff at the Minnesota Department of Health also responded to forms submitted by physicians reporting certain newborns that they believed were at high risk for developmental disorders or mental retardation. In addition, health department staff provided "consultation to local public health agencies, preschool agencies, schools, and social service agencies" about individual handicapped children. The Community Development Center in Fergus Falls and the Child Study Center in Owatonna were partially funded through grants from the Maternal Child Health Services of the United States Department of Health, Education, and Welfare–Region V in Chicago, and Schacht managed the grants and handled the coordination between the two centers and the central office at the Minnesota Department of Health. 523

Newborn genetic screening raised questions and came under attack from time to time, particularly in the 1970s. <sup>524</sup> For example, Gary Fifield, a pediatrician on the faculty of the University of Minnesota School of Public Health, for reasons now unknown, favored voluntary rather than mandatory newborn genetic screening, an opinion that officials at the Minnesota Department of Health informed him that they took seriously. <sup>525</sup> Another critic, Robert Galen, a professor of pathology at Columbia University Medical

<sup>&</sup>lt;sup>522</sup> Performance report, Health Resources for the Handicapped, 1974, box 1, folder "Chronological Correspondence 1974–1975, Lee E. Schacht, 1974,"Papers of the Minnesota Department of Health, Minnesota Historical Society.

<sup>&</sup>lt;sup>523</sup> Lee E. Schacht to John M. Dyer, May 10, 1974, box 1, folder "Chronological Correspondence 1974–1974, Lee E. Schacht, 1974," Papers of the Minnesota Department of Health, Minnesota Historical Society.

<sup>524</sup> Diane B. Paul, "PKU Screening."

<sup>&</sup>lt;sup>525</sup> Ronald G. Campbell to Gary Fifield, January 14, 1977, box 2, folder "Chronological Correspondence 1975–1977, Ronald G. Campbell, M.D., Jan–Jun 1977," Papers of the Minnesota Department of Health, Minnesota Historical Society.

School, presented a speech in Minneapolis to a group of health professionals in 1976 criticizing PKU testing. He argued that the disease did not always cause mental retardation, the treatment was harmful or fatal to children misdiagnosed with PKU, the dietary treatment was difficult and sometimes failed, and pregnancy in a PKU affected mother who had been treated as a child and not put on the diet again while carrying a child would produce a mentally retarded child.<sup>526</sup> Schacht and his supervisor at the Minnesota Department of Health, physician Ronald G. Campbell, wrote a lengthy letter to the editor of the St. Paul newspaper reporting the talk, refuting every point in great detail. They debunked Galen's alternative "index case approach" strategy to target screening to affected families, citing the fact that none of the three Minnesota newborns found during screening in 1975 "had a family history for the disease." They were identified at a cost to the state of about \$8,400 each. That compared with an estimated cost of \$16,700 per year for institutional care for untreated affected children. The average life expectancy for such children was 25 years, potentially costing the state \$1,255,000 for their lifetime care, on top of the tragedy of allowing three families to suffer. A similar cost would occur each and every year. 527 Schacht and Campbell did not address the cost of the dietary treatment, a shortcoming common among proponents of the screening.<sup>528</sup> These arguments and refutations closely resembled similar debates nationally, with competing narratives of PKU as a public health success story relatively free of problems

<sup>&</sup>lt;sup>526</sup> For a discussion of the history of the dietary treatment of PKU, see Susan Lindee, *Moments of Truth*, 40–45.

<sup>&</sup>lt;sup>527</sup> Ronald G. Campbell and Lee E. Schacht to editor of the *St. Paul Dispatch*, December 16, 1976, box 2, folder "Chronological Correspondence 1975–1976, Lee E. Schacht, Oct. 1975 to Dec 1976," Papers of the Minnesota Department of Health, Minnesota Historical Society.

<sup>&</sup>lt;sup>528</sup> Paul, *The Politics of Heredity*, 179.

versus an opposite critique based on objections to the lack of individual rights in a mandatory, or rarely declined, state-funded screening program. 529

Other problems within the Human Genetics Unit did occur, particularly disagreement over interpretation of test results for galactosemia, a procedure that had even higher rates of both false negative tests and false positive tests than PKU. These errors required the retesting of those found positive six weeks later in order to reduce misdiagnosis. The geneticists occasionally were unhappy when staff in the laboratory did not always follow the protocol to defer communication with physicians about abnormal tests to the geneticists, resulting in "misconceptions because of incorrect information being provided." <sup>531</sup>

### Relationships between the Human Genetics Unit and the University of Minnesota

The atmosphere within the University of Minnesota was welcoming for Lee Schacht and the Human Genetics Unit's experience and expertise in public health genetics. Sheldon Reed, especially, welcomed Lee Schacht as a colleague, supported his work at the health department, and integrated him into academic life at the University. Long after his retirement, Schacht described his relationship with Reed in glowing terms and giving him credit for public health genetics,

Sheldon was in essence my mentor. He was the one who brought me here. He was extremely positive and very supportive in seeing that the health

<sup>&</sup>lt;sup>529</sup> Paul, *The Politics of Heredity*, 180–2.

<sup>&</sup>lt;sup>530</sup> Lee Schacht to Ronald G. Campbell, memorandum on galactosemia screening procedures, July 30, 1976, box 2, folder "Chronological Correspondence 1975–1976, Lee E. Schacht, Oct. 1975 to Dec 1976," Papers of the Minnesota Department of Health, Minnesota Historical Society.

<sup>&</sup>lt;sup>531</sup> Memorandum on PKU screening to Ronald G. Campbell from Lee E. Schacht, July 30, 1976, box 2, folder "Chronological Correspondence 1975–1976, Lee E. Schacht, Oct. 1975 to Dec 1976," Papers of the Minnesota Department of Health, Minnesota Historical Society.

department did not just push this aside and ignore it. He would make suggestions as to things we could do or areas that we could approach but also could be very helpful if I would go to him and say, 'How do I reach some of these audiences, or these people?' And he could be very helpful in that. As I said, he was always a good mentor, always positive, and a really good friend through all of this. I think he in essence [had as] his conception that human heredity was a public health concern, long before anyone else had thought that. And he wanted to see it succeed and I think we both had the same goal.<sup>532</sup>

Faculty in the Medical School invited Schacht to participate at rounds and conferences involving patients with genetic diseases.<sup>533</sup> Unlike some of his national counterparts at the time, the Dean of the School of Public Health, Gaylord Anderson, viewed human genetics as an integral component of public health research, education, and practice and eventually asked Schacht to design and teach a course in public health genetics. Courses in public health genetics were taught in other schools of public health much earlier than at Minnesota as the three presentations at the 1964 symposium had shown in the presentations about the University of California at Berkeley, Yale University, and the Johns Hopkins University."534 In 1964, Gaylord Anderson proposed extending an appointment to Schacht in the School of Public Health as a non-salaried lecturer. Schacht was asked to present "course material with respect to the relationship between genetics and human health as a public health problem."535

<sup>&</sup>lt;sup>532</sup> Interview with Lee E. Schacht.

<sup>533</sup> Interview with Lee E. Schacht.

<sup>&</sup>lt;sup>534</sup> University Catalog and Program Description, Yale University Program in Public Health, Department of Epidemiology and Public Health, 1961, series VI, box 1, folder "1956-69," James V. Neel Papers, American Philosophical Society.

<sup>&</sup>lt;sup>535</sup> Gaylord W. Anderson to James V. Neel, May 21, 1964; Neel to Anderson, May 29, 1964, series I, box 4, folder "Correspondence Amer-Anth," James V. Neel Papers, American Philosophical Society.

Anderson appointed Schacht to the faculty of the University of Minnesota School of Public Health as a lecturer in 1965. He developed and taught the first course solely devoted to public health genetics at the school in 1968 under the title, "Human Genetics and Public Health." The course description in the catalogue was "evaluation of current studies in human genetics and applications to community health." The purpose of the course was "to present the basic concepts of genetics and to relate these to problems involving public health." Between 1964 and 1974, 140 students took the course, an average of 15 per year; 23 of the students chose to write a paper with a genetics topic to satisfy the research requirement for the master's degree in public health. The elective course was specifically designed for students working degrees in public health at Minnesota, attracting not just students in the sponsoring maternal and child health track but others as well.

Schacht later remembered that he had difficulty finding an appropriate textbook on human genetics for the public health students because existing books were oriented toward medical and graduate students in biological sciences. To ensure that the public health students had sufficient background in biological science to benefit from the genetics course, Schacht required each student to obtain his permission to register. <sup>540</sup> He

 $<sup>^{536}</sup>$  University of Minnesota Bulletin, Graduate Programs in Medicine, Dentistry, and Pharmacy 1965–1967, no. 7, (April 1, 1965), 75.

<sup>&</sup>lt;sup>537</sup> University of Minnesota *Bulletin, School of Public Health 1968–1970*, 71 (7), April 25, 1968, 45.

<sup>&</sup>lt;sup>538</sup> Lee E. Schacht to Robert ten Bensel, December 31, 1974, box 1, folder "Chronological Correspondence 1974–1974, Lee E. Schacht, Jan–Sept 1975," Papers of the Minnesota Department of Health, Minnesota Historical Society.

<sup>539</sup> Schacht to ten Bensel, December 31, 1974.

<sup>&</sup>lt;sup>540</sup> Interview with Lee E. Schacht.

found the textbook by H. Eldon Sutton, his former colleague at Michigan (then teaching at the University of Texas), to be the best for the public health students because it required less background in biology than did similar texts written for students in more technical fields of biology or medicine.<sup>541</sup>

#### **Recent Events with Public Health Genetics in Minnesota**

During Lee Schacht's career at the Minnesota Department of Health, some of the responsibilities of the Human Genetics Unit were transferred to other organizations both for financial reasons and for the purpose of increasing the capacity to provide genetic services more widely. For example, Minneapolis General Hospital's Neurology Department established a clinic for Huntington's disease and eventually oversaw the care of Huntington patients. With Schacht's direct involvement, the clinic managed the registries of affected families in the state.

In 1977, health department officials requested an analysis to justify the continuation of the genetic laboratory services, including cytogenetics and testing the blood of newborns.<sup>542</sup> To reduce costs and at the same time assure that the latest, often expensive, technology was available, the health department decided to transfer its genetic laboratory services to other institutions, combining its cytogenetics laboratory with the existing one at the University of Minnesota,<sup>543</sup> and contracting with the Mayo Clinic for

<sup>&</sup>lt;sup>541</sup> H. E. Sutton, *An Introduction to Human Genetics*, (New York Holt, Rinehart and Winston, 1965).

<sup>&</sup>lt;sup>542</sup> Ronald G. Campbell to Lee E. Schacht, "Re: Preparation of Justifying Information Relative to Maintenance of MDH Laboratory Support in Cytogenetics and PKU/Galactosemia Testing," box 2, folder "Chronological Correspondence, Ronald G. Campbell, M.D., Jan–Jun 1977," Papers of the Minnesota Department of Health, Minnesota Historical Society.

<sup>543</sup> Sheldon Reed, in *Dight Institute Bulletin No. 13*, (1966). In 1961, the head of the University of Minnesota Laboratory Medicine Department, GT Evans, and Sheldon Reed sought support for setting up a

the testing of the newborn blood samples.<sup>544</sup> The Human Genetics Unit did not add any specific new programs as these functions migrated to other organizations.

After Schacht's retirement in 1988, his position remained unfilled for eight years until the hiring of Kristin Oehlke, a genetic counselor without a doctoral level degree but with extensive experience in conducting genetic counseling in clinical settings and in communities. Beginning in 1996, she managed the human genetics program at the Minnesota Department of Health. But, by the time she accepted the job, the Human Genetics Unit had shrunk to only one function, the maintenance of the newborn screening program's outreach activities. 545 The disease registries, limited to those conditions identified in newborn screening, moved away from being a research or public health policy tool toward being a mechanism to provide adequate genetic consultation to individuals and health care providers in Minnesota. External events also had acted to reduce human genetics services at the Minnesota Department of Health. Many genetic problems that had never been included in public health genetics programs such as Rh incompatibility were completely solved after they were incorporated into the personal health care system as routine components of obstetric care where testing and intervention could occur routinely. Likewise, the availability of safe and effective birth control, amniocentesis, and legal measures to terminate pregnancies further put decisions about prenatal genetic testing into the hands of doctors and patients. Hospitals and health plans hired their own genetic counselors and added genetic counseling to obstetric and pediatric

laboratory of human cytogenetics in the Medical School; Jorge Yunis subsequently accomplished the task of creating a service and research laboratory for chromosomal analysis.

<sup>544</sup> S. Reed, in Dight Institute *Bulletin No. 13*, (1966).

<sup>&</sup>lt;sup>545</sup> Personal communication with Kristin Oehlke, Public Health Geneticist, Minnesota Department of Health, October 7, 2010.

services routinely. When public health genetics relinquished all but a small part of what it did at the beginning, it may have been a victim of its success in expanding genetic knowledge into the health care system and for the public. Except for newborn screening, public health genetics has gradually disappeared, increasingly viewed as a relic of the past.

#### **Public Health Genetics in Practice and Comparisons with Eugenics**

Martin S. Pernick has written about the relationship between eugenics and public health in the early twentieth century. He noted that some eugenicists, for example, Charles Davenport thought that the public health goal of preventing diseases that thinned out the unfit was not beneficial to the human race. That argument was common among those attacking public health and welfare programs in the early twentieth century for a variety of reasons beyond eugenic concerns. Pernick noted that although the eugenics movement and the field of public health had their disagreements, they shared many overlapping ideas and values. 546

Did public health genetics as seen in the Minnesota Human Genetics Unit constitute a new form of eugenics? Lee Schacht would probably have said no because of his adamant belief about honoring the wishes of individuals and families during genetic counseling. <sup>547</sup> In his opinion, Sheldon Reed tended to be more direct in his advice to patients during genetic counseling. Nonetheless, Reed, too, understood the damage to people that had occurred in the 1930s and 1940s with coercive negative eugenics. On the

<sup>&</sup>lt;sup>546</sup> Martin S. Pernick, "Eugenics and Public Health in American History," *American Journal of Public Health 87 (1997): 1767–72*.

<sup>&</sup>lt;sup>547</sup> Interview with Lee E. Schacht.

other hand, Schacht's public health genetics was clearly on a continuum with over a hundred years of interest in how to use genetic information to help improve individual as well as population health.

Reed believed in the early 1950s that human genetics, unlike eugenics earlier, possessed an adequate intellectual and scientific foundation for its application to public health. Eugenics, in Reed's view, had failed to incorporate sound genetic scientific knowledge such as was available during its heyday earlier in the century because,

The chickens were counted before they were hatched. The concept of the eugenics movement was attractive because it seemed to provide a biological solution for practically social problems. The eugenics movement failed because it was so easily perverted in its youth long before it had sufficient underpinnings to permit it to stand alone, or to resist seduction. <sup>548</sup>

While Reed was enthusiastic about public health genetics, he cautioned about the possible dangers of eugenics and misapplication of human genetics:

In Nazi Germany an attempt was made to use human genetics for the benefit of the state even though it resulted in the destruction of millions of innocent bystanders. Not only was the science of human genetics misused, but all civil liberties and political institutions were destroyed.<sup>549</sup>

Reed believed that genetic counseling, and by extension public health genetics, offered eugenic benefits that accrued to the state by enabling potential parents to prevent offspring who might later be dependent upon the government for their care. That reason alone justified the provision of genetic counseling by the state if no alternative existed in

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 $<sup>^{548}</sup>$  Sheldon C. Reed, "A Short History of Genetic Counseling," in Dight Institute *Bulletin 14*, (1974).

<sup>&</sup>lt;sup>549</sup> S. Reed, "A Short History of Genetic Counseling."

the private health care system. <sup>550</sup> In an interview near the end of his life, long after retirement, Schacht expressed a position similar to Reed's but not as coercive:

My concept was and still is that you are their listening post, you advise them, tell them of options, try to be sure they understand what all of the consequences of various actions are going to be *et cetera*, but they make the final decision. You do not. . . . Sheldon was a little more directive because he came out of that earlier period. No, he would not—not insist, he would strongly recommend but not insist that someone not have children and how they should go about it. <sup>551</sup>

In Schacht's opinion, then, genetic counselors at different periods of time varied in their proclivity for directing decisions of recipients.

In a series of six articles in *Minnesota Medicine*, the state medical society journal, Reed commemorated the tenth anniversary of the Minnesota Human Genetics League. He asserted that the League constituted a new eugenics society comparable to the American Eugenics Society or earlier eugenics organizations.<sup>552</sup> Those papers became the basis for his Presidential address at the ninth annual meeting of the American Society of Human Genetics August 28, 1956, entitled "The Local Eugenics Society." In that presentation, Reed traced the progression in Minnesota from eugenics to public advocacy for public health genetics.<sup>553</sup> The League's greatest achievement, in Reed's opinion, was the 1959 law mandating a Human Genetics Unit at the Minnesota Department of Health.

<sup>&</sup>lt;sup>550</sup> S. Reed, "A Short History of Genetic Counseling."

<sup>&</sup>lt;sup>551</sup> Interview with Lee E. Schacht.

<sup>552</sup> Sheldon Reed, "The Minnesota Human Genetics League, Part 1 of 6," *Minnesota Medicine* 39(1956):748; "The Minnesota Human Genetics League, Part 2 of 6," *Minnesota Medicine* 39(1956);818; "The Minnesota Eugenics Society, Part 3 of a Series," 40(1957):50; "Minnesota Human Genetics League, Part 4 of a Series," *Minnesota Medicine* 40(1957):128; "The Minnesota Human Genetics League, Part 5 of 6," *Minnesota Medicine* 40(1957):183; "Minnesota Human Genetics League," *Minnesota Medicine* 40(1957):265–6.

<sup>553</sup> Sheldon Reed, "The Local Eugenics Society," *American Journal of Human Genetics* 9 (1957): 1–8.

Minnesota is unique in that it has a human genetics unit established by the legislature in the Board of Health and headed, as you know, by Dr. Lee Schacht. This would not have occurred at all, were it not for members of the League who testified at the legislative hearings in favor of the bill. Some of those League members were Dr. John S. Pearson, Mrs. Leatha Patterson, and your secretary [Sheldon Reed]. The service of this unit to the people of Minnesota has been of the greatest value, and this single offspring of the Minnesota Human Genetics League and the Dight Institute more than justifies the existence of the League for all time. <sup>554</sup>

Reed's statement explicitly ties the earlier organizational phases of human genetics in Minnesota to the establishment of the Human Genetics Unit at the state health department.

Sheldon Reed expressed his belief in the need for an updated version of eugenics throughout his career, writing in 1965 that,

The need for eugenic concern is greater to-day than ever before because of the population 'explosion' and the automation 'explosion.' It is not realistic to encourage the more intelligent to increase their birth rate greatly because of the menace of overpopulation. It is imperative that the less intelligent be discouraged from reproducing as much as at present because machines are rapidly taking over the jobs previously held by the least able of our fellow men.<sup>555</sup>

A eugenic agenda was preserved, implicitly if not explicitly, in the progression from eugenics, to human genetics, to public advocacy for human genetics, and to public health genetics. Universal access to effective genetic counseling as a function of public health genetics was indeed a form of eugenics in that it improved the quality of the gene pool by preventing the birth of people with hereditary diseases. Public health genetics programs,

<sup>554</sup> Sheldon Reed, report of the secretary–treasurer, minutes of the thirty-first annual meeting of the Minnesota Human Genetics League, November 18, 1976, Papers of the Minnesota Human Genetics League, University of Minnesota Archives.

<sup>555</sup> Sheldon C. Reed, "Toward a New Eugenics: The Importance of Differential Reproduction," *Eugenics Review* 57 (1965): 72–4.

however, did not try and could not affect the intelligence of the population in the way Reed envisioned as important for the success of a highly technical and automated world.

If public health eugenics indeed was the direct descendent of eugenics, the question remains as to what kind of eugenics it was. Public health genetics in Minnesota obviously did not comprise negative eugenics, the use of coercive interventions to prevent the production of genetically impaired children. Specifically, the state did not directly intervene in, limit, or prevent reproduction by individuals to prevent births of such children. On the contrary, even when a known hereditary condition had been identified and parents wished to prevent the birth of affected offspring, the state limited and blocked people's reproductive choices through laws governing birth control and abortion. Newborn genetic screening, the hallmark of public health genetics, was likewise not negative in that, although compulsory and universal, screening did not occur until after birth, and except for identifying risk of damaging familial hereditary traits for future children, it happened too late and without any mandatory interventions attached to qualify as a negative eugenic measure. In the same manner, genetic disease registries did not directly serve to prevent individuals or families from reproducing, but rather relied on voluntary genetic counseling to influence individuals' behavior.

As practiced by the Human Genetics Unit in Minnesota, public health genetics can be interpreted as a form of what historians have identified as "positive eugenics" that hearkens back to the analyses of Francis Galton and others who wanted to use information about heredity to improve the quality of humans and their society. In providing sound scientific information to individuals and populations about their genetics, public health genetics afforded people the opportunity to make informed

decisions about their risk of adverse genetic conditions and offered them options for limiting that risk. The end result on a societal and population level was that the people's voluntary exercise of their "right to protect themselves against all forces that lead to illness or to death" achieved the secondary outcome of improving the gene pool, an outcome that Francis Galton, James Neel, Sheldon Reed, and Lee Schacht would have all embraced.

#### **CHAPTER 6**

# Conclusion: What Was and Is Public Health Genetics and What Will Become of It?

Most of us will agree that, for man, it is the world of mental life which counts by far the most, the rest being pretty much subsidiary. It is therefore evident that, if we ever come to weigh the relative values of different genotypes for reproduction, the genes concerned with mentality, could we estimate them at all, would on the whole have the higher priority. 556 —H. J. Muller, 1950.

Public health genetics, the application of genetic science as a function of government to benefit the health of human populations, arose in 1959 in Minnesota. It occurred in response to the vision of a founder of human genetics, Sheldon Reed, and with the support of an updated and vigorous eugenics society with strong academic and community support, namely, the Minnesota Human Genetics League. The over-arching conclusion that we can draw from these events is that public health genetics descended from the eugenics movement in Minnesota and from the academic human genetics program at the University of Minnesota as an endeavor to prevent genetic diseases and perhaps to improve the quality of the human gene pool. Its secondary goal, to reduce the financial burden of genetic disease on society, also contained eugenic parallels.

I will draw two sets of conclusions about public health genetics. The first group involves the intellectual, scientific, academic roots and conditions necessary for public health genetics to arise in 1959. The second group relates to the relationship of public health genetics to traditional functions and practice of public health in the 1960s.

 $<sup>^{556}</sup>$  H. J. Muller, "Our Load of Mutations," *American Journal of Human Genetics 2* (1950): 111–76.

#### Intellectual, Scientific, and Academic Roots of Public Health Genetics

The roots of public health genetics in Minnesota were planted in a long history of activism, scientific research, and social organization about human heredity. By the late 1950s, a critical mass of scientists and informed citizens was in place to enable support for the authorization of a Human Genetics Unit in Minnesota's state health department. The case can be made that Sheldon Reed was the first human geneticist in the United States to envision an official role for genetics in public health and to possess the interpersonal skills to make it happen. This assertion does not ignore the population based work of other twentieth century geneticists such as Charles Davenport who collected massive numbers of individual case reports and family pedigrees at the Eugenics Record Office for eugenic purposes or James Neel who studied hereditary diseases among inmates of state institutions in Michigan to determine the frequency of mutations. Reed's vision for population genetics differed from those earlier efforts because he wanted hereditary health embedded within the public health functions of the state and provided as a service for the common good rather than for the benefit of individuals within institutions or under the control of the state as had been the case in the Davenport and Neel examples. 557

As historian Richard J. Evans has emphasized, explanations of historical causation that focus on the thoughts or intentions of one individual person in the past are "plainly wrong" and we "must make some attempt to look for broader explanatory factors." Evans recommended taking into account "how human beings think, feel, and

 $<sup>^{557}</sup>$  Interview with Lee E. Schacht by Neal Ross Holtan, October 7, 2007.

behave in a given culture or society" to understand the past.<sup>558</sup> Based on Reed's ability to maintain interpersonal relationships and his tendency to influence society's attitudes toward genetics through public education and collective action, he probably would have agreed with Evans. Nevertheless, the leadership role that Reed played in creating something new and unprecedented with public health genetics should be acknowledged. Evidence suggests that Reed's vision, his knowledge of human genetics, and his social and political skills were necessary for the appearance of public health genetics in Minnesota and the United States. That conclusion does not negate Evans's well-taken point that many other people's thoughts, feelings, and actions in Minnesota contributed as important factors. The modest Reed always gave credit to others for the concept of public health genetics, but it was he who championed the idea in Minnesota and made it happen.

Public health genetics came about toward the end of the period in the midtwentieth century when, as Diane B. Paul has pointed out, eugenics was still a widespread
and acceptable belief among human geneticists and other educated members of society. 

As Paul has noted, five of the first six presidents of the new American Society of Human
Genetics, Sheldon Reed one of them, served simultaneously on the board of the
American Eugenics Society. 

The connection between eugenics and human genetics in
Minnesota predated Reed in that the Dight Institute had been funded by a bequest from
the president of the Minnesota Eugenics Society, Charles Dight.

<sup>&</sup>lt;sup>558</sup> Richard J. Evans, *In Defense of History* (New York, NY: W. W. Norton & Company, 1999), 118–19.

Diane B. Paul, "Eugenic Origins of Medical Genetics," in *The Politics of Heredity: Essays on Eugenics, Biomedicine, and the Nature–Nurture Debate* (Albany, NY: The State University of New York Press, 1998) 133–56.

Diane B. Paul, "From Eugenics to Human Genetics," in *Controlling Human Heredity: 1865 to the Present* (Amherst NY: Humanity Books, 1998), 115–35.

According to Paul, eugenics enjoyed resurgence and regained currency among human geneticists in the 1960s. At that time, the description by of some geneticists that genetic counseling had eugenic intentions was not meant negatively and did not damage the reputation of their early programs. On the contrary, the label of *eugenics* was meant to imply something positive. Even one of the most severe critics of traditional eugenics, geneticist H. J. Muller, urged that individuals with larger loads of genetic defects should be counseled not to reproduce. 561 Paul noted the conflicting and shifting aims of genetic counseling over time between two different goals, the prevention of individual suffering and the improvement of the gene pool, the private and the public. That dichotomy, she explained, was why Sheldon Reed "could plausibly claim in the 1950s that counseling was a form of eugenics and with equal plausibility in the 1970s that it was not." While the two goals always co-existed, the prevention of suffering was short-term and private while the improvement of the gene pool long-term and public. The same cultural trends were acting on the geneticists who developed public health genetics programs in the early 1960s.<sup>562</sup>

By the mid-1970s, the eugenics movement had been so thoroughly discredited and demonized that the term *eugenics* was no longer an acceptable label for any undertaking, private or public, that involved human genetics. Geneticists compensated by emphasizing the private goal of preventing human suffering over the public one of improving the gene pool. Genetic counselors such as Reed in the mid-1960s expressed concern about the hereditary health of the population and counseling's positive effect on

<sup>&</sup>lt;sup>561</sup> Diane B. Paul, "'Our Load of Mutations' Revisited," *Journal of the History of Biology* 20 (1978): 321–35.

<sup>&</sup>lt;sup>562</sup> Paul, "Eugenic Origins of Genetic Counseling."

it, but just a few years later they shifted to an exclusive focus on the needs and wishes of individuals and their families.<sup>563</sup> This change in emphasis reflected much broader societal trends such as assigning high value to personal autonomy, freedom from control, antiauthoritarianism, and individual rights—much older core American values that came to drive the cultural revolution in the United States in the 1960s and early 1970s. People holding these newly emphasized cultural values found the eugenics movement to have been abhorrent. To many thought leaders during that period of liberation politics, experience with eugenics in the United States had proven that society does not have a defensible interest in meddling with who should reproduce. Genetic counselors in the 1970s who had been trained in specific new master's level programs rather than as physicians or human geneticists, would have disagreed completely with the idea that genetic counseling was preventive or possessed implications for population health whereas ten years earlier those claims had been pillars of public health genetics programs. 564 The field of public health genetics therefore enjoyed a narrow timeframe, not much more than a decade, in which to develop in the 1960s before societal and professional attitudes shifted from the common good of population health to the private good of honoring the individual's feelings and beliefs about reproductive choices.

Connected with the societal shift from group to individual values in the 1960s and 1970s, explanations other than heredity arose to account for social problems and flawed human beings. One of those systems of thought was to view individuals' human characteristics as caused by local social and cultural forces rather than biology. Rebecca

<sup>&</sup>lt;sup>563</sup> Paul, "Eugenic Origins of Genetic Counseling."

<sup>&</sup>lt;sup>564</sup> Paul, "Eugenic Origins of Genetic Counseling."

Kluchin called that view of the human condition neo-eugenics, the "notion that 'defective' traits like poverty and illegitimacy were 'bred' through culture (rather than genes)." 565 Neo-eugenics was the unorganized but pervasive effort by some scientists, politicians, and social conservatives in the 1970s and 1980s to define a person's value, and by extension, his or her reproductive fitness, with the specific cultural and social environment in which he or she had been formed rather than biological criteria. In other words, bad culture, rather than flawed genetics, explained people's failings, and substandard and dysfunctional subcultures were said to reproduce bad people. Themes and terms from the early eugenics movement such as degeneracy, criminal tendencies, illegitimacy, generational poverty, welfare dependency, hyper-sexuality, fecundity, the breakdown of families, and a tendency toward violence appeared again in neo-eugenic rhetoric. Public health professionals, on the other hand, endeavored to use genetic science as the basis for explaining some, but not all, human traits. Nevertheless, arguments about which traits had genetic components erupted in the early 1970s over the connection between violence, intelligence, behavior, and race. 566 With its insistence on universal access to genetic services, equal treatment for all, informed consent for interventions provided by the government, and reliance on genetic science, the values of public health genetics would seem to have been the antithesis of neo-eugenic viewpoints. Public health genetics programs emphasized biological rather than cultural heredity; that is, they were eugenic instead of neo-eugenic. But, public health proponents were swimming against a strong cultural tide in the opposite direction.

Rebecca Kluchin, Fit to Be Tied: Sterilization and Reproductive Rights in America, 1950–1980 (New Brunswick, NJ, Rutgers University Press, 2009).

<sup>566</sup> Kluchin, Fit to Be Tied.

Another intellectual root of public health genetics was its symbiotic relationship with reproductive medicine. <sup>567</sup> New medical technology enabled public policy about human heredity to be envisioned and applied in meaningful, inexpensive, and effective ways, for example, in newborn genetic screening. The combination of birth control, amniocentesis, prenatal diagnosis, metabolic screening tests, and chromosomal analysis appeared to some people to enable the creation, in Susan Lindee's words, of "new, more acceptable and legitimate forms of eugenics." <sup>568</sup> But these medical services, provided voluntarily on an individual basis within the context of personal medical care in the private sector of medicine, served to drive elements of public health genetics such as genetic counseling and screening for some diseases such as Rh incompatibility back into the realm of medical services rather than preserving or expanding them as components of public health practice. The implication of this trend is that individuals or couples had the access to technology to make private reproductive decisions that had eugenic implications for society. <sup>569</sup>

Public health genetic policy was, and is, driven from two directions, one being technology in human genetics and medicine that represent the term *health*, the other, social and political considerations that make it *public*. When technology is defined, as it was by French philosopher, Jacques Ellul, to include human social systems in addition to technical systems, the interactions between public health, private health care, and politics

<sup>&</sup>lt;sup>567</sup> Henry L. Nadler, "Antenatal Detection of Hereditary Disorders," *Pediatrics* 42 (1968): 912–18; Nadler, H.L., Gerbie, A.B. "Role of Amniocentesis in the Intrauterine Detection of Genetic Disorders," *New England Journal of Medicine* 282 (1970): 596–99; *Antenatal Diagnosis* (1970), Conference on Antenatal Diagnosis, ed. Alfred Dorfman (Chicago: University of Chicago Press, 1972).

Lindee, *Moments of Truth in Genetic Medicine* (Baltimore, MD; the Johns Hopkins University Press, 2005), 15–16.

<sup>&</sup>lt;sup>569</sup> Paul, "Politics of Heredity," 104.

are easier to understand.<sup>570</sup> Actions in any of those three spheres to prevent genetic disabilities are closely related and capable of being transferred from one domain to another.

Concern about nuclear weapons and possible damage to human genes was pervasive during the 1950s just before public health genetics arose. Anyone alive then remembers the high level of anxiety caused by the possible long-term genetic damage from atomic bombs and weapons testing. The popular consciousness of the importance of genes was a relatively new phenomenon that expanded after the discovery of DNA by Watson and Crick in 1953. In Minnesota, proponents of public health genetics used the fear of genetic damage to argue the need to monitor the population for adverse effects of radiation on human genes. People also worried about genetic damage from industrial pollution that so obviously had caused the crash in numbers and near extinction of many animals.<sup>571</sup> As the drive to establish public health genetics in Minnesota highlighted, many people considered the state to be responsible for monitoring damage to their genes. But, the task of monitoring populations for mutations or genetic diseases proved to be more difficult than imagined. Public health's tools in the 1960s were inadequate to conduct surveillance of the gene pool for damage from radiation or chemical pollution.<sup>572</sup> That outcome is not surprising given the difficulty encountered in studying the Japanese

<sup>&</sup>lt;sup>570</sup> Jacques Ellul, *The Technological* Society, tr. John Wilkinson (New York, NY: Vintage Books, 1964), first published in French, 1954.

<sup>&</sup>lt;sup>571</sup> Rachel Carson, *Silent Spring* (New York, NY: Ballantine Books, 1963).

<sup>&</sup>lt;sup>572</sup> Peter S. Harper, *A Short History of Medical Genetics* (New York, NY: Oxford University Press, 2008), 247–48.

for adverse effects from the atomic bombs.<sup>573</sup> James Neel, the director of the Atomic Bomb Casualty Commission, detailed some of the challenges that he faced in connecting the atomic bombs with specific genetic abnormalities—problems in finding and diagnosing genetic defects in infants, consanguinity, and the lack of technology to detect particular genetic defects directly.<sup>574</sup>

# The Relationship of Genetics to the Practice of Public Health

Another way to assess the history of public health genetics besides socio—cultural and intellectual considerations is to compare it with other traditional functions and practices in public health. The first comparison was with the public health system's hallmark concept, that is, concern for disease and disability in a population rather than in individuals. Some of the challenges of inventing public health genetics in 1960 and the following few years were unveiled in making that distinction. Most genetic diseases were rare and difficult to diagnose. Other than surveillance (keeping registries of genetic diseases), public health practice had few tools to study and almost none except genetic counseling to prevent hereditary disorders. Most of the genetic disease entities that initially concerned public health officials and seemed to be appropriate for disease registries, such as Huntington's disease, were more effectively addressed in clinical settings where the individual with the condition could receive medical care and family members get genetic counseling. In that respect, the model for public health genetics was

James V. Neel and William J. Shull, The Effect of Exposure to the Atomic Bombs on Pregnancy Termination in Hiroshima and Nagasaki (Washington, DC, National Academy of Sciences— National Research Council, 1958).

James V. Neel, *Physician to the Gene Pool: Genetic Lessons and Other Stories* (New York, NY: J. Wiley & Sons, 1994).

more akin to old eugenic interventions such as surgical sterilization of the feeble-minded that focused on a few individuals thought to be at high risk for transmitting a genetic impairment to their offspring than public health strategies that reduced disease in large populations by reducing their collective risk.

Another traditional public health strategy, mass health education, proved to be a particularly ineffective tool for preventing genetic diseases because messages about genetics and behavior change were needed only for the individuals and families at risk for particular genetic diseases. Few messages other than increased public awareness and acceptance of genetic screening were appropriate for mass health education. Another strategy of public health, to change the social environment within which disease occurs, for example, removing tobacco smoke from public places, was similarly not applicable to genetic diseases.

Newborn genetic screening was (and is) the public health activity involving genetics most applicable to an entire population. Except for a few false negative tests, mandatory, universal screening finds all cases of a particular genetic disease such as PKU in the population of newborn infants. This public health approach was warranted because many of the diseases detected in newborn screening programs were so rare that voluntary testing would be likely to miss most of them. Newborn genetic screening also shared another trait of public health programs, namely, the need to invade privacy and force inclusion both for the benefit of individuals and for the greater good of society.

Public health officials have used coercive interventions with individuals and societies for centuries to prevent the spread of infections, and they have enjoyed extraordinary authority (the police power of public health) when needed to protect the

health of the public without regard to consent and cooperation of the individual. The examples of typhoid fever <sup>575</sup>, tuberculosis <sup>576</sup>, syphilis <sup>577</sup>, polio <sup>578</sup> and AIDS <sup>579</sup> in the nineteenth and twentieth centuries show the extent to which public health officials have employed police powers to subordinate individual rights for the protection of the population. Coercive public health actions against communicable diseases have included mandatory reporting of diseases to health departments, required vaccinations to attend school, and the use of quarantine. Authority to mandate newborn genetic screening was therefore analogous to the police power of public health to detect and prevent infectious diseases. Proponents both of eugenics and public health genetics had used the concept of contagion for genetic conditions even when it was not entirely apt. <sup>580</sup> In Minnesota, advocates of public health genetics used the analogy to infectious diseases more indirectly than meaning contagion, arguing only that the prevention of genetic diseases ought to be as important as controlling communicable diseases.

Public health genetics shared many characteristics in public health practice with chronic and metabolic disease surveillance and prevention. By mid-twentieth century, these diseases had become public health concerns and health departments had gained

<sup>&</sup>lt;sup>575</sup>Judith W. Leavitt, *Typhoid Mary: Captive to the Public's Health* (Boston, MA: Beacon Press, 1996).

<sup>&</sup>lt;sup>576</sup> Sheila M. Rothman, *Living in the Shadow of Death: Tuberculosis and the Social Experience of Illness in American History* (New York, NY: Basic Books, 1994).

<sup>&</sup>lt;sup>577</sup> Allan M. Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States* (New York, NY: Oxford University Press, 1985).

<sup>&</sup>lt;sup>578</sup> Tony Gould, *A Summer Plague: Polio and Its Survivors* (New Haven, CT: Yale University Press, 1995).

<sup>&</sup>lt;sup>579</sup> Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York, NY: St. Martin's Press, 1987).

Diane B. Paul, "Genes and Contagious Disease: The Rise and Fall of a Metaphor," in *The Politics of Heredity*, 157–72.

techniques to monitor, study, and prevent them. Control of chronic diseases differed from infectious diseases in that the programs were not aimed to eliminate the diseases, only to delay their onset or ameliorate their manifestations. That goal had similarities with strategies to prevent genetic diseases. Some of the public health tools developed for chronic disease prevention and control such as disease registries and epidemiological studies offered limited application in understanding and preventing genetic diseases. For genetic disease, however, the prevention task was different in that the risk factors, the genes themselves, could not be altered by health education or behavioral change except for the intimately personal choices of birth control, abortion, or marrying a different partner. Compared with chronic diseases such as diabetes that had only a small hereditary component, genetic diseases were mostly all-or-nothing defects in one gene, the inborn errors of metabolism such as PKU. The prevention of chronic diseases and genetic diseases did, however, share the aim of decreasing the enormous social costs of caring for chronically ill and disabled individuals.

Finally, public health genetics shared with other public health programs the virtue of providing and assuring access to services for individuals, families, and groups who did not have the financial or social means to access private medical services to prevent adverse hereditary conditions. In Minnesota, universal access to genetic counseling and preventive services had been one of the primary arguments for developing public health genetics. The public health genetics program in Minnesota focused heavily, especially at first, on assuring access to genetic counseling for the entire population. Other than genetic counseling, though, the tools for preventing genetic diseases were limited to amniocentesis, birth control, and abortion, services that were not provided by the public

health system. In that light, perhaps the closest public health program for the prevention of genetic diseases was Title X of the 1970 Public Health Service Act that assured access to family planning services for those without the means of obtaining them otherwise.

#### The Effectiveness of Public Health Genetics

Were public health genetics programs effective in improving the genetic health of populations? In light of the disparities between genetics and other public health concerns in terms of having effective public health strategies to address them, the answer is probably a qualified no. Some hereditary abnormalities such as extra fingers or toes are perceived as harmless variations. Other genetic impairments such as Huntington's disease are viewed as disasters. Judging the effectiveness of prevention therefore depends in part on the severity of the impairment of a particular genetic disease. The problem with placing genetic diseases together as a class and making a statement about how effectively they have been prevented through public health is that genetic diseases have very little in common with each other except for the factor of inheritability. Some diseases, such as the inborn errors of metabolism that are caused by an inherited single genetic mutation have been found and prevented in siblings of those affected and therefore have improved the gene pool. Other diseases such as adult-onset diabetes that have a hereditary component but are not single gene disorders defy public health strategies to prevent them through their genetics.

Universal testing of newborns for treatable genetic diseases seems to have been the best fit for genetics with the public health model. The state assured that nearly all newborns with certain genetic defects were identified and benefited from treatment.

Newborn genetic screening achieved almost universal compliance without question

among parents and physicians, high acceptance for genetic counseling based on the results, and maintenance of treatment for children with dietary regimens. Newborn genetic screening programs and congenital disease registries remain today as the last functions of public health genetics.

Except for the inborn errors of metabolism, prevention of genetic disease through public health programs does not seem to have lived up to the hopes of its early proponents and practitioners. Public health genetics may have suffered from its own success in being able to transfer most of its functions to the private medical care system rather than retaining them as a public responsibility and expense. A form of success might be claimed for public health genetics in the exposure of broad numbers of people and their physicians to the idea that genetic screening and genetic counseling are beneficial.

Once established, public health genetics programs had to insure that they were applied effectively, productively, ethically, fairly, and safely in order to maintain people's trust. The history of public health genetics in Minnesota and elsewhere proved that possible. No instances of abuse of individuals or their personal data have been reported in more than fifty years of practice. That record of maintaining privacy and integrity may in itself be a measure of success of public health genetics that could become important in the future.

Did public health genetics succeed in improving the genetic health of populations? Was it a good fit with public health? The founders of public health genetics and its early leaders in the 1960s saw immense promise to achieve the lofty goal of preventing genetic disease in populations. The present study shows, however, that public

health genetics enjoyed only limited success in improving human heredity because human genetics did not lend itself well to traditional public health strategies and successful preventive interventions. In that way, public health genetics failed to live up to the hopes of its founders, just as did the eugenics movement that had preceded it.

## **New Opposition to Public Health Genetics**

Decades passed in the late twentieth century during which public health genetics programs garnered little public attention or resistance. Newborn genetic screening remained well accepted, possibly because taking blood samples from the heels of newborns, a procedure that occurred out of the vision of parents, did not require parental permission and because the consequences of missing a case of treatable genetic disability such as PKU were unthinkably cruel and severe. Outside of technical issues about screening such as false negatives and positives, no instances of harm to individuals, abuse of test results, or breaches of privacy occurred.

Signs of change in public support of public health genetic programs appeared in 1983 in New Jersey when anti-abortion and conservative religious groups organized an unsuccessful effort to prevent expansion of that state's birth defect registry. That opposition occurred during a time when concern swirled about other public health activities that might violate privacy and enable social discrimination such as mandatory reporting and registries for HIV.

Opposition to public health genetic programs appeared in Minnesota in 1996 and first involved a proposal by the state health department to establish a birth defect registry.

<sup>&</sup>lt;sup>581</sup> Amy Fairchild, Ronald Bayer, James Colgrove, "Who Shall Count the Little Children?" *Searching Eyes: Privacy, the State, and Disease Surveillance in America*, Milbank Books on Health and the Public (Berkeley, CA: University of California Press, 2007), 144–70.

Intense efforts to fight the birth defect registry, something that the Human Genetics Unit had not established in Minnesota, and soon afterwards, an immunization registry, were led by a well-organized libertarian group called the Citizens' Council on Health Care, headed by public health nurse, Twyla Brase. See Consistently present, critical, and vocal at legislative hearings at the Capitol, the privacy advocates succeeded in forcing the Minnesota Department of Health to withdraw and radically revamp its proposals for the registries in 1997. The privacy critics explicitly invoked eugenics as a reason to oppose the birth defect registry and prevailed over some legislators' concern about the need to monitor for a perceived increase in congenital defects in areas with high pesticide use. The privacy groups fiercely objected to the state keeping a list of "defective citizens" and framed their argument as privacy being a higher good than any other consideration. Sea

After the battles over public health registries, the Citizens' Council began to object to the lack of consent in obtaining the blood samples for newborn genetic screening. They expressed concern that the indefinite storage of samples of everyone's blood at the state health department could result in massive future invasions of Minnesota citizens' privacy. They alleged that genetic research on their genes without their consent would certainly occur and that the stored genetic material would provide data to deny individuals health insurance or marriage licenses and be used to search for individuals with certain undesirable genetic characteristics. <sup>584</sup> The Citizens Council strongly opposed the blood samples being used in population genetic research, something that had not

 $<sup>^{582}</sup>$  Fairchild, Bayer, and Colgrove, Searching Eyes.

<sup>&</sup>lt;sup>583</sup> Fairchild, Bayer, and Colgrove, *Searching Eyes*.

<sup>&</sup>lt;sup>584</sup> Fairchild, Bayer, and Colgrove, *Searching Eyes*.

occurred but had been discussed by researchers. The opponents objected to genetic research on the blood samples because explicit permission for this use had not been obtained. While advocates on the other side who wanted to use the stored blood samples for population-based genetic research were willing to compromise on issues such as time limits for storing the samples and fail-safe provisions for unlinking data from individuals for research, the privacy advocates were not willing to compromise on any of their positions.

The Citizens' Council has sued the Minnesota Department of Health and its recent Commissioner of Health, physician Sanne Magnan personally on the question of not obtaining parental permission for newborn screening. The group's goal in the suit is to require written parental permission for newborn genetic screening. A lower court recently ruled against them and the Minnesota Supreme Court has agreed to hear the case. It is widely thought that it will eventually be appealed to the United States Supreme Court if it is not decided in the privacy advocates' favor in Minnesota.<sup>586</sup>

A different, but significant, legal case with negative implications for genetic research involves the successful lawsuit of the Havasupai Indian Tribe against Arizona State University in 2008. Tribal members received monetary damages when the court decided that researchers had not properly handled samples of their blood in a genetic research project by allowing researchers access to the blood without the specific consent

<sup>&</sup>lt;sup>585</sup> Fairchild, Bayer, and Colgrove, *Searching Eyes*, 164–8.

 $<sup>^{586}</sup>$  Personal Communication, Sanne Magnan, former Commissioner of the Minnesota Department of Health, February 12, 2011.

of individuals for it to be used for that purpose.<sup>587</sup> Although that case did not involve public health investigations, it has further heightened awareness and concern among public health officials about the potential for legal action against them.

# **Historical Meaning and Public Health Genetics**

People do care intensely and passionately about their own genetic material. They understand that their genetic makeup spans the past, present, and future of their existence and links them with their ancestors and descendents. People also know that genetics shapes them unalterably, at least until as yet unforeseen new technology comes into existence. Knowledge about genetics is so well and widely understood that heredity has become the framework that many people use to interpret what happens to them. Genetic thinking pervades nearly every aspect of human intellectual life, and genetics has become the tool with which people understand and control their reproductive choices, personal medical conditions, and futures. 588 Human beings use genetic knowledge to serve their desire to know and control their hereditary destinies, for example, testing for risk of breast cancer and agreeing to bilateral mastectomies if at risk, even though that choice is the exception rather than the norm. They want to prevent their offspring from suffering from genetic diseases and routinely avail themselves of reproductive choices to that end, perhaps selfishly, to avoid the pain, inconvenience and cost. 589 Many people have decided to fight to keep their DNA private at all costs, even to the detriment of the health

<sup>&</sup>lt;sup>587</sup> Michael M. Mello and Leslie E. Wolf, "The Havasupai Indian Tribe Case—Lessons for Research Involving Stored Biological Samples," *New England Journal of Medicine* 363 (2010): 204–7.

<sup>&</sup>lt;sup>588</sup> Dorothy Nelkin and M. Susan Lindee, *The DNA Mystique: The Gene as a Cultural Icon* (New York, NY: Freeman, 1995).

<sup>&</sup>lt;sup>589</sup> Claire O. Leonard, Gary A. Chase, and Barton Childs, "Genetic Counseling: A Consumer's View" *New England Journal of Medicine* 287 (1972): 433–439.

and well being of others. People's genes are intensely personal, unique and considered private property of the individual with all rights reserved.<sup>590</sup>

On the other hand, people also understand that their genes have a public dimension. For example, people resent the financial cost to society of caring for severely impaired individuals with genetic diseases outside of their own families, and they resent personal autonomy prevailing in families with multiple children with the same genetic defect. People also understand that DNA testing has replaced fingerprinting and official documents as proof of personal identity. They know that DNA testing in the legal system has become the new proof of innocence or guilt for criminal acts and have witnessed its power in correcting errors and shortcomings in the justice system that in the past have damaged innocent individuals.

What do these popular beliefs about genes have to do with public health genetics? People's beliefs about their own genes color their attitudes about the heredity of others outside of their own families and affect public health genetics programs either favorably or unfavorably. Societal attitudes about ownership, privacy, and consent govern public health policies and practices and possess the power to change or stop public health activities. This dissertation has shown the complicated relationship between people's understanding of genes and the application of the science of human genetics to the population through public health programs.

An explanation for the reason that genetics has taken on such cultural significance might be found in Susan Sontag's book about cancer and tuberculosis as metaphors for social ills, war, witch hunts, violent revolution, genocide, and a host of other evil forces.

<sup>&</sup>lt;sup>590</sup> Nelkin and Lindee, *The DNA Mystique*.

Her point was not that disease metaphors represented a helpful or good thing. Rather, she emphasized that physical illness itself is not a metaphor. On the contrary, "the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to metaphoric thinking." Disease metaphors are impurities that accompany ideologies and value judgments intended to make a negative social argument or to frighten people about some vague fear. For example, the word *eugenics* is now a metaphor used by opponents of public health genetics programs, for example, and is the most pejorative and vehement word associated with genetics that they can apply. The metaphor intends to discredit and undercut the depiction of public health genetics programs as a common good.

Some people now view public health genetics as a symbol for government that is over-reaching, intrusive, and dangerous. They see undefined evil lurking in governmental programs that they fear will intrude into their lives and exert control over them and their affairs. As Sontag concluded, the disease metaphor was,

A vehicle for the large insufficiencies of this culture, for our shallow attitude toward death, for our anxieties about feeling, for our reckless improvident responses to our real 'problems of growth,' for our inability to construct an advanced industrial society which properly regulates consumption, and our justified fears of the increasingly violent course of history. <sup>592</sup>

Has human genetics in the public sphere become a new negative metaphor on that order? If attacks on newborn genetic screening and hereditary disease registries are any indication, the answer is yes.

<sup>&</sup>lt;sup>591</sup> Susan Sontag, *Illness as Metaphor* (New York, NY: Vintage Books, 1979).

<sup>&</sup>lt;sup>592</sup> Sontag, *Illness as Metaphor*, 84–5.

People who say that genetics should never have become part of the public realm in the first place miss the point that it actually did and for reasons that had to do with the social, political, and cultural context of the time. The people in Minnesota who came together in the 1950s to create a public health genetics program shared values—faith in science to solve human problems, dedication to health for all, prevention of human suffering, protection of the gene pool—that fifty years later seem to be relics of a remote age that believed in the goodness, not the evil, of collective action. Distrust of government and its authority to regulate private, individual decisions has put collective action for health under assault. Public health genetics, in particular newborn screening, no longer functions unnoticed in a quiet "medical backwater," to reiterate Susan Lindee's description.

#### The Future of Public Health Genetics

Lack of trust in government and concerns about privacy and informed consent have the potential to demolish newborn genetic screening as a public health function, one of the last vestiges of the public health genetics program in Minnesota. Allegations of malfeasance, accusations of abuse of blood samples, and insinuations of ill will on the part of the government from privacy advocates have brought proponents of public health genetics to an uncomfortable crossroads. The privacy advocates do not see newborn screening as a benign measure for the public good but as intrusion and control. Some people view the spots of blood at the state health department as having the potential for harmful governmental control over them and their genes.<sup>593</sup>

 $<sup>^{593}</sup>$ Mai Yee Chen, "Five Drops of Blood," Twin Cities StarTribune, November 10, 2007.

The future of public health genetics is therefore uncertain. New genetic screening tests are increasingly available (twenty genetic conditions were added to the panel of tests performed by the state health department on the blood of newborns in Minnesota in one fell swoop in 2006) and are considered cheap and safe. This testing is coupled with the discovery of new and effective treatments for many previously untreatable diseases such as cystic fibrosis at a time when public and political support for mandatory genetic screening may be seriously waning. <sup>594</sup> Medical experts and child health advocates such as the March of Dimes and the Minnesota Medical Association have rallied to the defense of newborn genetic screening but it may be too late. <sup>595</sup> They lack an effective advocacy group such as the Minnesota Human Genetics League to focus the argument and help to counteract those opposed to mandatory newborn screening.

Given the ever-increasing capabilities of genetic testing and the growing concerns about privacy, battles about human genes and government control are sure to escalate and morph into as yet unknown manifestations. Public health genetics may eventually become the casualty of the cultural shift in the 1980s when people in the United States in large numbers started to distrust government and see it as the enemy. Without trust, there is no social cohesion, and with no social cohesion, there can be no public health genetics programs. Public health genetics programs must contend with damaged trust at the same time that popular definitions of medical versus public health and individual versus popular become proxies for individual rights and privacy on the one hand, and societal obligation to prevent harm to individuals on the other.

<sup>&</sup>lt;sup>594</sup>Personal communication with Kristin Oehlke, Minnesota Department of Health geneticist, October 7, 2010.

<sup>&</sup>lt;sup>595</sup> Kate Ledger, "Living Proof," *Minnesota Medicine* 92 (2009): 26–31.

On the other hand, programs in public health genetics might at some future time re-awaken and revive if social and cultural trends shift, widespread new threats to population genetic integrity appear, or technology takes on unimagined, new capabilities for identifying genetic conditions among large groups of people and offering interventions to prevent genetic impairments or correct existing damage to genes. If and when that day comes, political leaders and government health officials will have the experience gained with public health genetics in the mid-twentieth century to inform their decision-making in a different historical context and shape their ethical values in light of the new technology and the new cultural values. Technology and culture change rapidly, interact in unpredictable ways, and may drive the need for human genetics again in the future to be a subject of public health and societal concern.

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(See Appendix A for a list of the contents of the *Bulletins*.)

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#### APPENDIX A

# **Summary of the Contents of the Dight Institute**

### Bulletins no. 1–18, 1943–1979

### **Bulletin Number 1 (1942)**

Preface by Theodore C. Blegen

Report on the Organization and Aims of the Dight Institute and Its Accomplishments for the Year Ending June 30, 1942, by Clarence P. Oliver, Director

Purpose and Policies of the Institute

Accomplishments for the Year 1941–1942

Instruction

Research and Research Projects

Consultation

Other Interests

Office, Personnel, and Expenditures

Acknowledgments

Chronology of Charles Fremont Dight, M.D.

"A Biographical Sketch of Charles Fremont Dight, M.D." by Evadene Burris Swanson

Early Life

**Scientific Interests** 

Social and Political Activities

Dight's Interest in the Eugenics Movement

Activities in Minnesota in the Field of Eugenics

Endowment

Legislative Program for Eugenics

Dight's Home

Bibliography of Published Writings of Charles Fremont Dight, M.D.

#### **Bulletin Number 2 (1943)**

Report on the Accomplishments of the Dight Institute for the Year

The Purpose and Policies of the Institute

Accomplishments for the Year 1941–1942 by Clarence P. Oliver, Director

The Collection of Records in the Study of Human Heredity by Clarence P. Oliver, Director

Introduction

Purposes of the study of human genetics

Choosing the cases for study

Questions determining the types of data to be collected

Hereditability

Variability

Records for identification

Identification of family

Identification of informant

Identification of propositus

Data to collect

From whom to collect data

Relatives by degree of relationship

Names and addresses

Limitations in number of relatives

Frequency of trait among relatives

Description of the trait

In the propositus

In other affected memers

**Environmental factors** 

Genetic factors

Names and addresses

Completing and checking data

Miscellaneous data

**Twins** 

Consanguinity

Linkage data

Attitude of members of a family

Literature cited and reading references

Appendix.

- A. Familial data form
- B. Information for the study of linkage relationship in the propositus and his brothers, sisters, parents and children
- C. Sample pedigree chart

#### **Bulletin Number 3 (1945)**

Report of the Dight Institute for the Academic Year 1943–44 Third annual report

General Remarks

**Instructional Program** 

Research and Research Interests

**Breast Cancer** 

Mongolism

Congenitally Missing Teeth

Feeblemindedness

Family Records

Amyotrophic lateral sclerosis

Bilateral ptosis and strabismus

Diabetes mellitus

Hemophilia

Huntington's chorea

Periodic paralysis

Progressive muscular dystrophy

### Consultation and Public Service

Charcot-Marie-Tooth's disease

Unilateral vision defect

Curvature of the spine

Hypotrichosis

Enamel deficiency

Obesity

Ectodermal dysplasia

Risk of disease

**Palsy** 

Hypertension

Advisability of marriage

Deaf-mutism

Consanguinity

Race genetics

Other Items

Acknowledgments

"A Family History of Huntington's Chorea Made Possible by the Recording of Surnames" by C. P. Oliver and B. C. Schiele

# **Bulletin Number 4 (1946)**

Fourth Annual Report of the Dight Institute for the Academic Year 1944–45

General Remarks

**Instructional Program** 

Annual Dight Institute Lecture Talks by the Director

Research and Research Interests

**Breast Cancer** 

Congenitally Missing Teeth

Feeblemindedness

Cleft Palate

Mongolism

Family Records

Consultation and Public Services

Other Items

List of Publications

"Biology and Social Problems" by Elmer Roberts

#### **Bulletin Number 5 (1947)**

Fifth Annual Report of the Dight Institute Report of the Dight Institute for the Year 1945–46

The Minnesota Human Genetics League

**Instructional Program** 

Annual Dight Institute Lecture

Talks by the Director

**Premarital Genetics Examinations** 

Heredity in Cancer Susceptibility

Research and Research Interests

**Human Breast Cancer** 

Cleft Palate

**Epilepsy** 

Feeblemindedness

Family History Files

Consultation and Public Services

#### Other Items

List of Publications

"Four Generations of Blindness," by J. C. Lysen, Superintendent of the Minnesota Braille and Sight-Saving School and C. P. Oliver

### **Bulletin Number 6 (1949)**

Reactivation of the Dight Institute 1947–1949

**Educational Program** 

#### Research

Fibrosis of the Pancreas Mental Deficiency Breast Cancer

Counseling in Human Genetics

"Counseling in Human Genetics" By Sheldon C. Reed, Director (pages 7–21)

## **Bulletin Number 7 (1951)**

"Appreciation of Helen Bunn," by Dwight E. Minnich

Report of Progress 1949–1951, by Sheldon C. Reed

**Education Program** 

Research

Huntington's chorea

Leukemia

Familial hypoglycemosis

Diabetes mellitus

Fibrosis of pancreas

Mental deficiency

Manic depressive psychosis

Normal intelligence and differential fertility

Vision deficiency

Breast cancer

"Counseling in Human Genetics, Part II," by Sheldon C. Reed

#### **Bulletin Number 8 (1953)**

Report of Progress 1951–1953

**Educational Program** 

Research

The Minnesota "Nams"

Progressive muscular atrophy

Huntington's chorea

Diabetes mellitus

Fibrocystic disease of the pancreas

Congenital heart disease

Breast cancer

Mental deficiency

Counseling in Human Genetics

"Counseling in Human Genetics, Part III," by Sheldon C. Reed

### Bulletin Number 9 (1956)

Report on Progress, 1953–1955

**Education Program** 

Research

The Genetics Research Program at Rochester State Hospital

Progressive Muscular Atrophy

**Breast Cancer** 

Mental Retardation

Multiple sclerosis

"Genetic Counseling in Crippling Diseases," by Ntinos C. Myrianthopoulos

**Skeletal System Abnormalities** 

Chondrodystrophy (Achondroplasia)

Osteogenesis imperfecta

Congenital dislocation of the hip

Neurological and Neuromuscular Disorders

Progressive infantile muscular atrophy

Progressive muscular dystrophy

**Epilepsy** 

Club foot

Spina bifida

Ataxias

Friedreiche's ataxia

Marie's cerebellar ataxia

Spastic paraplegia

Infectious Diseases

Rheumatic heart disease

Poliomyelitis

### **Bulletin Number 10 (1957)**

Report on Progress, 1955–1957

General Remarks

"Counseling in Medical Genetics," textbook by Sheldon C. Reed

Financial Resources

First International Congress of Human Genetics

Elizabeth Reed

**Educational Program** 

Research

Breast cancer

Mental retardation

Multiple sclerosis

The Nams (two members of a New York family who came to Minnesota with IQ values obtained on their descendents, master's thesis of James V. Higgins)

Cerebral Palsy

Counseling in Human Genetics

# Bulletin Number 11 (1959)

Report on Progress, 1957–1959

General Remarks

**Educational Program** 

Research

Breast cancer

Mental retardation

The Nams (published in American Journal of Mental Deficiency)

Cerebral Palsy

Mental Disorders

Counseling in Human Genetics

"Discourse of His Holiness Pope Pius XII to the International Congress on Blood Transfusion, September 5, 1958"

Some Medical-Biological Aspects of Genetics of the Blood

Problem of Genetics of the Blood

"Discourse of His Holiness Pope Pius XII to the Seventh International Congress on Hematology, September 12, 1958."

**Proposed Solutions** 

Reply to the Questions Proposed

<sup>&</sup>quot;Causes of Congenital Anomalies," by Sheldon C. Reed

<sup>&</sup>quot;A Law for Human Genetics," by Sheldon C. Reed

## **Bulletin Number 12 (1961)**

Report on Progress, 1959–1961

General Remarks

V. Elving Anderson

Lee E. Schacht and the Human Genetics Unit

**Educational Program** 

Research Program

Cytogenetics

Cerebral Palsy

Mental Retardation

Mental Disorders

Counseling in Human Genetics

### **Bulletin Number 13 (1966)**

"Appreciation of Dwight E. Minnich," by Sheldon C. Reed

Report on Progress, 1961–1963

General Remarks

**Educational Program** 

Research

Mental Retardation

Mental Disorders

Cytogenetics

Perinatal Research

Counseling in Human Genetics

Report on Progress, 1963–1966

General Remarks

Progress report covers 3 years

Dight Institute moved from Graduate School to the College of Biological

Sciences

**Educational Program** 

Reed talk at First Nobel Conference at Gustavus Adolphus College

Genetics Rounds at the Medical School

Research

Mental Retardation

Mental Disorders

Biostatistical Research

Hereditary Factors In Stein-Leventhal Syndrome

### **Bulletin Number 14 (1974)**

"Appreciation of Charles M. Goethe,' by Sheldon C. Reed

"A Short History of Genetic Counseling," by Sheldon C. Reed

Report on Progress, 1966–1968

**Educational Program** 

Research

Counseling in Human Genetics

Report on Progress, 1968–1970

**Educational Program** 

Statement on Therapeutic Abortion by the Minnesota Human Genetics League Research

Four PhD theses: Jerome H. Waller, 1969; Thomas H Thelen, 1969; Robert D. Nelson, 1969; Paul L Nichols, 1970; Robert J Desnick, 1970.

Counseling

Report of Progress, 1970–1972

General Remarks

4<sup>th</sup> International Congress of Human Genetics, Paris, September 1971 Educational Program

Pamphlet, Minnesota Human Genetics League, "Medical and Genetic Indications for Therapeutic Abortion"

PhD theses completed in 1972: Susan J. Desnick, Mark E. Leppert, Susan Nichol, David L. Pauls

Research Program

John R. Sheppard, Ph.D., appointed Assistant Professor in the Department of Genetics and Cell Biology and Assistant Director (Laboratories) of the Dight Institute effective July 16, 1972.

Report of Progress, 1972–1974

General Remarks

Dight Institute moved from Zoology Building to the Old Botany Building with 7 times the space

**Educational Program** 

Remarks about Human Genetics League's future

Research

NIH training grant awarded to Sheppard and Desnick

Desnick joins staff of Dight Institute

List of publications

Genetic Counseling

#### Bulletin Number 15 (1978)

General Remarks by Sheldon Reed on his retirement 1 July 1978

Report of Progress, 1974–1976

**Educational Program** 

Genetic Rounds, University of Minnesota Medical School, Robert Desnick and Richard King

Research

Six papers by V. Elving Anderson

Sheppard promoted to Associate Professor at age 31

Twenty-seven papers by Desnick

Report of Progress 1976–1978

General Remarks

Desnick moves to Mt. Sinai School of Medicine

**Educational Program** 

Research

Multiple papers by Anderson, Sheppard, and Desnick

Counseling in Human Genetics

Dight staff totaled 4,351 episodes of genetic counseling in 31 years

## Bulletin Number 16 (1979)

"Genetic Services for the Community"

Brief Review of a Colloquium in Honor of Sheldon C. Reed

October 12-13, 1978

Coffman Memorial Union, University of Minnesota

Sponsored by: the Dight Institute for Human Genetics, the Minnesota Human Genetics League, the Continuing Medical Education Division of the University of Minnesota and National Foundation/March of Dimes

It is an elegant description of some of the extremely useful genetic services which are available in Minnesota and some other states for those in need of help with problems related to their genetics."

First Plenary Session: The Diagnosis and Management of Genetic Disorders Chairman: Richard A. King, M.D., Ph.D.

"A Short History of Human Genetics in the USA' by Sheldon C. Reed, (American Journal of Medical Genetics (1979) 3:281–295)

"Recent Advances in the Diagnosis of Genetic Diseases' by Ian H. Porter, Professor and Chairman, Department of Pediatrics, Albany Medical College, and Director of the Birth Defects Institute, New York State Health Department.

"Chromosome Analysis and Modern Medicine". Jaroslav Cervenka, of the University of Minnesota Divisions of Oral Pathology and Oral and Human Genetics in the School of Dentistry.]

"Recent Advances in the Treatment of Genetic Diseases" by Richard J. Desnick.

"How to See—A demonstration of how physicians' biases affect their ability to perceive patients," by Robert J. Gorlin.

Workshops I and II.

I. Robert Gorlin, "Genetic Hearing Loss and Syndromes"

Leonard L. Heston, MD, Director of the Psychiatry Research Unit at the University of Minnesota, "The Genetics of Psychiatric Disorders"

Elving Anderson, "Genetics of Mental Retardation"

II. William H. Knobloch, UM Professor of Opththalmology, Sue Kellog, Social worker, and Ralph Hilgendorf, Counseling Supervisor of the State Services for the Blind and Visually Handicapped. "Genetic Basis of Visual Handicaps."

Lawrence J. Schut, MD, "Genetic Neurological Disorders with Adult Onset"

Richard A. King, MD, PhD, "Genetics of Common Adult Diseases." Ian H. Porter, "Genetics of Congenital Malformations."

Lee E. Schacht, "Newborn Screening"

Gregory Grabowski, University of Minnesota Pediatrics, "Criteria for Newborn Screening Such as Reliability and Accuracy of Tests."

Second Plenary Session: A Team Approach to Genetic Services, Chaired by V. Elving Anderson.

Willard Centerwall at UC Davis "Field clinics and children's hospitals"

Seymour Kessler, PhD., Director of the Genetic Counseling Program of the Health and Medical Sciences Program, University of California, Berkeley, "The role of the clinical psychologist in genetic counseling."

Joan Burns, MSSW, University of Wisconsin, Madison, "Integrating genetic counseling and social work, family dynamics and relationships"

Anne Mathews, "The role of the nurse in helping patients deal with grief, fear, anger, pain."

Dorothy Verstraete, MD, RD, University of Minnesota Department of Food Science and Nutrition "Food treatments of genetic disorders."

Judith Yates, Rochester Methodist Hospital, Advisory Board, Biological Sciences Curriculum Study for schools.

Karen Jensen, California State University, Fresno, "Special Education in Genetic Disorders"

Third Plenary Session: Comprehensive Planning for Genetic Services, Chairman, Lee Schacht.

Movie, "My Children, My Children: Sea in the Blood" story of Cooley's Anemia in several Greek families.

Movie, Huntington's Disease, Marjorie Guthrie and others at the National Committee to Combat Huntington's Disease which made the film.

Lee E.[Schacht and Richard King, "Genetic services in Minnesota."

"Historically, the Human Genetics Unit in the Board of Health was mandated by the 1959 legislature as a result of the lobbying of Mrs. Richard McCarthy, Dr. John Pearson, Dr. Sheldon Reed and others. The unit was set up in 1960 and in 1965 established the newborn screening program for phenylketonuria as a result of legislative action. An amendment to the original act was passed in 1967 which required the Human Genetics Unit to add a cytogenetics program and the first money from the legislature for human genetics was appropriated. The unit is authorized to coordinate all human genetics in the state to whatever degree they wish to cooperate."

#### **Human Genetics Unit**

Cytogenetics
Biochemical genetics
Hemoglobin screening
Consultation and Technical assistance
Education
Newborn Screening
Registries
Genetic Counseling Field Clinics
Overall Coordination of Genetic Services

King described the work at the University with 12–13 active scientists working in human genetics and the Genetics Clinic in the Medical School established 1972–73 to provide diagnosis and counseling, staffed by King, Gorlin, Cervenka, and 2 nurse practitioners.

## **Dight Institute Annual Lecture**

10 May 1942, Philip Levine, Newark Beth Israel Hospital, "Serological Differentiation of Human Blood: Theoretical and Practical Considerations."

1943–1944 Canceled.

16 April 1945, Elmer Roberts, University of Illinois, "Biology and our Social Problems."

14 November 1945, L. H.Snyder, Ohio State University, "The Rh Factor in Feeble-mindedness and Other Diseases."

17 November 1949, Sheldon C. Reed, "A Forty Year Follow-Up of Our Mentally Deficient."

25 November 1953, Lady Rama Rau of India, "Needs of India for Genetic Counseling, Marriage Counseling and Family Planning."

1955, John S. Pearson, Rochester State Hospital, "Treatment of Huntington's Chorea with Reserpine."