



Innovators *at* Heart

A publication for those who support heart-related research, education, and care at the University of Minnesota

Congenital heart disease grows up A new University program fills a critical gap for young adults who find themselves too old for pediatric cardiac care

For nearly all of her life, 22-year-old Shannon Beestman has received care at the University of Minnesota to treat her congenital heart defect. Having been under the care of a pediatric cardiac team for more than two decades, Beestman had concerns about transitioning to a cardiologist trained primarily in adult heart care.

But last year, thanks in part to the University's new Adult Congenital and Cardiovascular Genetics Clinic, that transition became a little easier.

The new clinic, which opened in February 2009, brings together pediatric cardiologists and adult cardiologists—literally. During at least the first several visits (and often indefinitely), patients receiving care through the clinic will meet with both experts at the same time.

"We combine the specialties in one clinical visit to provide the patient with the best of both [practices]," explains Cindy Martin, M.D., an adult cardiologist who codirects the clinic with pediatric cardiologist James Moller, M.D. "By integrating the specialties of pediatric and adult cardiac care, our program has the ability to provide everything patients need, from knowing about what happened during their first congenital heart surgeries as infants to providing care for whatever advanced adult cardiac disease may occur up until their 90s or 100s."

Martin says it's not uncommon for patients to seek follow-up care from their pediatricians until age 18, at which point they go off to college or get married and subsequently get lost in follow-up.

That lack of care is concerning, she adds, because most patients who have congenital heart disease carry a higher risk of developing heart-related complications such as high blood pressure or even heart failure in the future.

Photo by Scott Streble



Cindy Martin, M.D., and James Moller, M.D., see patients together at the University's new Adult Congenital and Cardiovascular Genetics Clinic.

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Meeting a growing need

Advances in pediatric heart care—many of which were developed at the University—have created this unique group of patients.

Five decades ago, some children born with congenital heart defects tended not to live long enough to *need* heart care as adults.

But in 2005, for the first time ever, the number of adults who had congenital heart disease surpassed the number of children who had it.

“We have 50-year survivors,” Moller says. “For several conditions, we have seen survival rates similar to that of the general population.”

Continuous care

The continuity of care offered at the new Adult Congenital and Cardiovascular Genetics Clinic meets a critical

need for the thousands of people who are living with congenital heart disease long-term.

In addition to pediatric and adult cardiologists, the clinic staff also includes a clinical coordinator, a congenital heart echocardiographer, and a genetic counselor. These experts provide pre-pregnancy counseling and care coordination with maternal-fetal medicine physicians in case a patient’s pregnancy becomes high risk.

When needed, the team also includes pediatric cardiothoracic surgeons. Roosevelt Bryant III, M.D., and James St. Louis, M.D., provide consultations when their colleagues think that surgery may be necessary.

“It ensures [a] degree of continuity for the patient—especially if that surgeon has performed many of that individual’s operations,” explains Bryant.

For Beestman, this collaborative group has set her mind at ease.

“Because of this clinic, I will never, ever be made to feel that pediatric cardiology is kicking me out the door and handing me off to a complete stranger,” she says. “Seeing my pediatric cardiologist working in collaboration with my adult cardiologist is incredibly comforting and reassuring.”

Research improves care

Because it’s associated with an academic institution, the Adult Congenital and Cardiovascular Genetics Clinic at the University of Minnesota also has a research component.

Clinic codirector Cindy Martin, M.D., an assistant professor of medicine at the University, is currently collecting patients’ DNA samples. She will later analyze the samples to identify any mutations that may be associated with congenital heart disease and conditions that can develop alongside it.

Then she’ll take what she learns in the lab back to the clinic to enhance the care she provides to patients.

A gift that returns the favor

You’ve heard the old adage that it’s better to give than to receive. But through a charitable gift annuity with the Minnesota Medical Foundation, you can help advance world-class heart research, education, and care at the University of Minnesota while you receive lifetime income and tax benefits.

A charitable gift annuity is a simple contract that does not require the services of an attorney. It provides a fixed annual payout that may well be higher than what is earned currently with certificates of deposit or money market accounts.

Here are some examples for single life charitable gift annuities:

Age 65	5.3% annual payout
Age 70	5.7% annual payout
Age 75	6.3% annual payout
Age 80	7.1% annual payout

To learn more about charitable gift annuities and other planned giving opportunities, contact the Minnesota Medical Foundation at 612-625-1440 or 800-922-1663 or at giftplanning@mmf.umn.edu, or visit www.mmf.umn.edu/giftplanning.

Philanthropy at work

Private gifts lift two University researchers' work to a higher level

Philanthropy has helped to shape the careers of University of Minnesota stem cell scientists Michael Kyba, Ph.D., and Rita Perlingeiro, Ph.D.

"We've had a lot of good interactions with philanthropy," Kyba says. "It has really changed the trajectory of my career for the better."

When Kyba and Perlingeiro were working at the University of Texas Southwestern in Dallas, the Dallas-based Dr. Bob and Jean Smith Foundation targeted their laboratories with generous seed support, enabling them to expand their stem cell research into the fields of muscle regeneration and muscular dystrophy.

And when Kyba and Perlingeiro, who are married, moved their labs to the University of Minnesota in 2008, the same foundation made a \$250,000 gift to each through the Minnesota Medical Foundation, helping to transition their research programs and providing opportunities for further growth.

"We feel extremely honored and fortunate to have received the support of the Dr. Bob and Jean Smith Foundation," Perlingeiro says. "Their generous donation has allowed us to undertake an innovative ... and intellectually rewarding project involving stem cells and muscular dystrophy."

And their research has been greatly successful. Perlingeiro's lab team has been able to essentially "instruct" embryonic stem cells to make muscle cells instead of other types of cells using a gene called PAX3. When those muscle cells were injected into the injured muscles of mice that have muscular

dystrophy, the cells not only helped to grow muscle tissue but also improved muscle function.

Her team has shown that this approach can restore muscle function in mouse models of both recessive and dominant forms of muscular dystrophy.

To help steer future cure-focused research down the right path, Kyba and his team are studying how the gene variation that causes a type of muscular dystrophy called facioscapulohumeral dystrophy (FSHD) causes muscle loss.

By removing muscle cells from people who have muscular dystrophy and reprogramming them to become induced pluripotent stem cells (which are believed to be able to form all types of tissue), the team expects to gain insight into the genetic basis for this form of muscular dystrophy and hopes to find ways to genetically repair that disease-causing defect.

Support from the Dr. Bob and Jean Smith Foundation has essentially created two self-sustaining research programs, Kyba adds. The research funded by this philanthropy has resulted in major National Institutes of Health (NIH) research project grants in each laboratory, plus a collaborative \$2 million stimulus research grant through the American Recovery and Reinvestment Act of 2009.

"If you think of philanthropy in investment terms," Kyba says, "our philanthropic support has netted a 200 percent dividend in the form of additional funds for muscle regeneration and FSHD research from the NIH. And our plan is to keep that dividend growing."



Michael Kyba, Ph.D.



Rita Perlingeiro, Ph.D.

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University
team
performs
700th
heart
transplant

Surgeons associated with the University of Minnesota reached a significant milestone on February 2 by performing their 700th heart transplant at University of Minnesota Medical Center, Fairview (UMMC). The patient, a 47-year-old man from North Dakota, is doing well.

“We’re thrilled the patient is doing so well,” says Ranjit John, M.D., one of the surgeons who performed the six-hour transplant. “He should have a bright future in front of him.”

The heart transplant program at the University is one of the oldest of its kind in the world. University surgeons performed the region’s first heart transplant in 1978, and today the group is still recognized for its excellence in pediatric and adult heart transplantation.

Physicians at the University established themselves as leaders in the early 1980s by treating heart transplant recipients with a triple-

therapy anti-rejection drug combination, which resulted in a significant improvement in survival rates and a new national trend.

Today, in addition to being internationally renowned for applying innovative uses of anti-rejection drug therapies, they are leaders in the use of mechanical circulatory support to keep patients’ hearts strong until they can get a transplant. The program’s physicians also perform heart transplants in combination with kidney and other organ transplants.

“Teamwork is what makes our program so successful,” says Kenneth Liao, M.D., Ph.D., surgical director of cardiac transplantation at UMMC. “Our program has given hope to so many people. It is wonderful to celebrate this achievement.”

Watch a video celebrating this pioneering transplant program at www.mmf.umn.edu/heart/.

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Nicole Endres
Editor

Jeanne Mettner
Writer

Lisa Haines, juju
Design

For more information, please contact:

Development
Minnesota Medical
Foundation
612-273-8592
heart@mmf.umn.edu

www.mmf.umn.edu/heart/

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