

## Introduction

# Rising Stars: Recognizing Important New Voices in Law, Medicine, Science & Technology

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In this special issue, important new voices in law, medicine, science, and technology comment on critical issues of national and international significance. They are the rising stars, applying sophisticated, interdisciplinary approaches to important policy matters that consume our courts, legislatures, and imaginations. The scholars participating in our invitation only special issue are among the most talented junior scholars in the academy

Their collective works on privacy, reproductive technology, global health, the rise and challenges of contemporary biotechnologies, and what these issues mean for important stakeholders: the public, government, and business, offer refreshing, nuanced analytical probes into murky arenas, which are made all the more complicated by biotechnologies outpacing of the development of laws to regulate or harness their reach. The scholars participating in this important project for the *Minnesota Journal of Law, Science & Technology* were not given a specific charge. Rather, they were provided open canvasses and encouraged to paint in broad, open strokes. Their art provides revelatory insights with shared and often cautionary themes.

Collectively, their wisdom reminds us about the importance of foundational values across the multiple spheres of biotechnology and its engagement in our lives, whether through assisted reproduction—its risks, challenges, and

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rewards—or in the regulation and monitoring of science and those who conduct it, lest patients and the most vulnerable become the unwitting victims of biological mining and genetic exploitation.

An interesting thematic link between their works is the cautionary note about unbridled technology and the importance of rules of law and the roles of law. Unlike their predecessors' generations, these scholars observe that sophisticated biomedical technologies are more accessible to a broader group of citizens than ever before. But with accessibility come economic, political, and social realities, pressures, and responsibilities, particularly when the subjects of the technology are people, and the building blocks of life or reproductive technology are intimately associated with their bodies. These scholars predict a bright future for technology, but responsibly urge a critical exploration of the darker, murkier contours, where human exploitation, greed, incompetence, and lack of deference to the rules of law expose the vulnerabilities of law, science and modern technology.

Readers will note the subtle, but evidenced themes relating to the challenges of biotechnology and risk in a global age; the call for recalibrating what disclosures should be demanded in an era where biotechnological advancements can at times incentivize unethical conduct that exploits the vulnerable, and the challenge in defining personhood and biology as the technological state and the products it produces has morphed. And in that evolution, biologics can have synthetic twins and companies can be persons.

Scholars participating in this special issue observe that we live in a global community with increasingly narrow, rather than thick borders. They note that science all the more breaks down these barriers, but so do diseases and illnesses. James Hodge, for example, reminds us of the pitfalls when international collaboration and cooperation fails.

In "*Global Legal Triage in Response to the 2009 H1N1 Outbreak*," Hodge reminds us that the disparate response to the virus that threatened possible international devastation was incoherent and incongruent at best. Despite WHO guidelines, "proven public health interventions were negated," and as a result, "human rights abuses arose," compounded by

the spread of the influenza and devastating economic impacts.<sup>1</sup> Hodge highlights a new era in law and science, where borders are permeable and not static, solid, and impenetrable.

In this new era, where the luxury of international travel is frequent and afforded by more people, the probability of spreading viruses increases. The danger is that communicable diseases do not recognize borders and customs. How to combat that? Hodge emphasizes that with the luxury of travel come certain governmental challenges and responsibilities. For this reason, he warns that tepid response to international protocols to prevent the spread of deadly viruses will likely lead to economic and health disasters. His intuition is yet to be fully tested, but ample evidence from the spread of H1N1 helps to bolster his claim.

At the intersection of technology and law collisions occur, and far too often race and gender operate at those locations.<sup>2</sup> Such was the case of Henrietta Lacks and the exploitation of her cell line. Largely forgotten or overlooked in the annals of medicine, Lacks' story was first visited by journalist and author, Harriet Washington, in articles and her award winning work, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*. More recently, Rebecca Skloot takes up the charge to resurrect Lacks' important contributions to science, in *The Immortal Life of Henrietta Lacks*, and Gail Javitt interrogates that work and reflects on the rule of law and respect for participants in tissue-based research. Javitt's observations are part of this special issue.

Javitt notes that in few cases has there been one to "single-handedly" offer a "scientific paradigm shift."<sup>3</sup> But that paradigm shift, and the underlying motivations for the use of Ms. Lacks' cell line, and the misinformation and lack of information provided to Lacks and her family paints a dark picture on the complicated canvass of American scientific history. At a time when African Americans were refused services at many hospitals across the United States,

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1. James G. Hodge, *Global Legal Triage in Response to the 2009 H1N1 Outbreak*, 11 MINN. J. L. SCI. & TECH. 599, 627 (2010).

2. See e.g., Michele Goodwin and Song Richardson, *Patient Negligence*, 72 DUKE J. OF L. & CONTEMPORARY PROBLEMS 223 (2010).

3. Gail Javitt, *Why Not Take All of Me? Reflections on The Immortal Life of Henrietta Lacks and the Status of Participants in Research Using Human Specimens*, 11 MINN. J. L. SCI. & TECH. 713, 713 (2010).

researchers discovered a treasure trove in her cell line that would change the manner in which pharmaceutical developments occur and how biological research is conducted for decades to come. Scientific researchers' failure to provide a meaningful disclosure to Lacks' family and obtain appropriate consent has caused a revisit of her case.

Lacks' valuable cell-line serves as the base of numerous life-saving vaccines and other treatments. But to tell Ms. Lacks' story absent of the context of her times, and her status is to ignore the conditions under which scientific research becomes captive to coercion, exploitation and greed. Javitt, like her colleagues in this special issue, sketches a cautionary portrait of scientific research involving human subjects and their tissues. She argues that the "use of cells and tissues for research brings with it myriad legal and ethical questions."<sup>4</sup> For example, to whom does the proprietary interest belong? Should ownership of a cell-line belong to anyone at all or be part of a public commons?

Javitt points out that important social and legal consequences result no matter how the questions are answered. More importantly is that the questions are answered, and that patient autonomy and dignity are honored and respected legally, medically, and ethically in medical tissue research. At the heart of her article are a set of urgent questions, including an inquiry as to what should govern "the voluntary provision of tissues by patient groups to researchers solely for the purpose of identifying the cause of their disease . . ."<sup>5</sup> Recent court cases make similar inquiries.<sup>6</sup> Unfortunately, as Javitt notes, the judicial treatment of these issues is often mired in formalism, "in the service of what sometimes appear to be preordained policy goals."<sup>7</sup> For Javitt policy questions regarding the dignified use of human tissue for research purposes cannot be answered in isolation, but rather, must engage the public if trust is to be gained. As important, she offers that "new federal legislation that establishes prospectively clear, uniform terms of engagement between the three parties to the tissue research enterprise," will be needed.

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4. *Id.* at 714.

5. *Id.* at 714.

6. See Michele Goodwin, *Formalism and the Legal Status of Body Parts* 26 U. CHI. LEGAL F. 317, 317-88 (2005).

7. Javitt, *supra* note 3, at 715.

In synergistic fashion, Anne Drapkin Lyerly, also promotes the use of law to temper the excesses of innovative technologies. In *Marking the Fine Line: Ethics and the Regulation of Innovative Technologies in Human Reproduction*, Lyerly argues that, “far less attention has been directed at the regulation of *research*—of oversight for the process of moving from bench to bedside, innovation to practice,” of assisted reproductive technologies. Like Javitt, Lyerly observes the importance of critiquing law and status in context. In this case, the author turns her attention to mothers, their offspring, and the lack regulation in the field of assisted reproductive technology (ART).

Lyerly unpacks a view of assisted reproductive technology overlooked in the media accounts of Nadya Suleman, the California mother that gave birth to octuplets after aggressive hormone therapies and the implantation of multiple embryos, or the case of Kate Gosselin, the celebrity-mother of eight. Rather, Lyerly’s pragmatic study of the ethics and regulations of ART is concerned “about [the] safe and ethical provision of reproductive medicine in the 21st century,” and with that, “the role of regulation of this process.”<sup>8</sup>

Animating Lyerly’s concern in this issue, are health and safety considerations for the babies born from ART. When ART is more experiment than practice, vulnerable, less-informed patients, may become the unwitting subjects of scientific research. Lyerly draws readers’ attention to intracytoplasmic sperm injection (ICSI), a special reproductive technique that remains at the center of some controversy.

Lyerly’s provocative work attempts to “pry apart” reproductive innovations that deserve greater legal scrutiny. She argues that while “new techniques may provide relief of the suffering caused by infertility and the birth of children with preventable disabilities,” such relief has also “ushered in problems with its progress.”<sup>9</sup> Lyerly’s intuition that innovation is at times blurred with experimentation, serves as an important intellectual guidepost for scholars and policy-makers concerned about promoting biotechnology, while also protecting the public from harm.

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8. Anne Drapkin Lyerly, *Marking the Fine Line: Ethics and the Regulation of Innovative Technologies in Human Reproduction*, 11 MINN. J. L. SCI. & TECH. 685, 687 (2010).

9. *Id.* at 712.

In matters of technology, these rising stars emphasize the importance of access to information and researcher disclosure, as an important component of the legal and ethical monitoring processes. This important theme is picked up in Vardit Ravitsky's informative article, "Knowing Where You Came From": The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness." Such thematic threads also appear in Braverman's article, also published in this issue.

Ravitsky's article adds her voice to the growing chorus interrogating what disclosure means in the context of donor-assisted births. Should children have a right to know their genetic parents? The normative questions driving her project emerge at multiple technological intersections: the use of technology to conceive, the use of third parties in that process, and social networking. At that unique intersection, young adults are driven to find answers to their genetic mysteries. Ravitsky suggests that part of what compels this desire "to know" is the psychological distress experienced in "not knowing." For this reason, many donor-conceived teenagers and adults have taken on the charge to learn their origins.

But the legal and ethical issues arising from the desire to know are not well-settled—if at all. Indeed, as Ravitsky suggests, "most fertility experts did not anticipate this outcome. They focused on their patients, helping them create the families they desired while perceiving the donor as a mere means in the process."<sup>10</sup> Thus, the interests, rights, and entitlements of donor-conceived offspring were largely ignored, not only by doctors and lawyers in the ART fields, but also the coordinating parents. Neither did state or federal legislatures enter this fray to help define the contours of privacy rights in the ART domain.

Further complicating this space are the conflicting information disclosure interests between ART parents, genetic parents, and their mutual offspring. A child might want to know her genetic heritage, but ART and genetic parents may desire constraint—and for differing reasons. As Ravitsky rightly notes, at least in the cases of genetic parents, the "trend" to avoid disclosure, "was maintained because most

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10. Vardit Ravitsky, "Knowing Where You Come From": *The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness*, 11 MINN. J. L. SCI. & TECH. 665, 665 (2010).

donors wish to remain anonymous and have no intention of establishing a relationship with offspring, and most parents choose to keep the circumstances of conception secret.”<sup>11</sup>

However, in an era where the interests of donor-conceived children have come to the forefront, prospective ART parents and the service providers they use are confronted with pressing questions (and very active internet campaigns) about identity disclosure. And the underlying motivations for urging a better disclosure regime vary from medical, psychological, and genetic concerns to a desire to avoid mistaken family building among individuals who might be genetic siblings or cousins.

In the United States, donor identity is not regulated by state or federal law. Indeed, in most countries, the norm remains to protect donor anonymity, despite the fact that, “donor identity is gathering momentum as a growing number of countries are adopting laws and regulations banning anonymity.”<sup>12</sup> For Ravitsky the important issue at hand is how these debates are framed and what is at stake in “knowing.” The effort is to avoid conflating all interests in ART disclosure as being equal or mutual, which are important lessons in law, science and medicine.

Identity animates a third theme in this special issue devoted to rising stars in law, science, medicine, and technology. In a final thematic forage, both Andrea Matwyshyn and Andrew Torrance urge the reconsideration of what the biological means in an expanding biotechnological era. In a brilliantly written article, “*Corporate Cyborgs and Technology Risks*,” Matwyshyn contemplates a rising future where corporations increasingly take ownership of a personhood identity, but are in fact less human than ever before. Her work is not one of science fiction, but a critical analysis about corporate identity and the roles of law in promoting and harnessing technology.

She writes, “the law has long treated corporations as persons with rights, and it continues to expand this treatment.”<sup>13</sup> And with this, she evaluates that the “practical differentiation between human persons and corporate persons grows tenuous in many respects to the outside world,” despite

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11. *Id.* at 665–66.

12. *Id.* at 666.

13. Andrea M. Matwyshyn, *Corporate Cyborgs and Technology Risks*, 11 MINN. J. L. SCI. & TECH. 573, 573 (2010).

the fact that corporations are becoming “less human.” In an era of corporate downsizing, corporations rely less on human power and brain trust than information systems with external humanization components. To Matwyshyn this morphing of “human-machine identity” risks a broad acceptance of “overzealous technology adoption” without critical auditing, monitoring, and where necessary disciplinary protocols.

Matwyshyn argues that these incongruent forces—a more deeply humanized status of corporate identity married to far less human interaction demands new legal considerations. She argues that this contradiction and “shift has carried with it technology driven risks to both individual entities and the economy as a whole.”<sup>14</sup> Drawing from the securities industry as a case study of “cyborg” transformations, she critically examines the landmines that plagued securities markets in the 1960s and 70s and the crisis point at which the SEC intervened. In forecasting a similar future for companies at the forefront of various technologies, she urges an *ex ante* response. The recent Gulf oil spill and the lack of precautionary measures to contain that devastation adds urgency to her analysis.

Matwyshyn calls for an information accountability regime. She argues quite persuasively for internal and external corporate oversight “that more effectively blends” multiple legal regimes. Her project is ambitious, calling for the cross fertilization of corporate, securities, contract, intellectual property, tort and criminal law regimes to proactively protect our biotechnological futures and possibilities. Matwyshyn’s project provides a platform for new policy leadership on corporate accountability in a biotech age.

Most fitting, perhaps, is to conclude these introductory comments with a reflection on our final *Rising Stars* author, Andrew Torrance, and his contribution to this special issue: “*Synthesizing Law For Synthetic Biology.*” Torrance’s work epitomizes scholarship at the intersections of medicine, law, science, and technology, empirically and theoretically. His contribution to this issue builds on a nuanced and developing body of work that aims to effect paradigm shifts in biological sciences. Torrance, like Matwyshyn, hopes to incorporate standardizations and innovative monitoring and auditing mechanisms into the biological sciences. Both scholars attempt

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14. *Id.*



to borrow from domains that might offer contoured and tested approaches to counteract actual, perceived, and possible unbridled and unregulated technologies.

Torrance takes up the case of synthetic biologics, such as synthetic DNA, with a concern about the ways in which a perceived ethos of openness in the industries that create these products could easily give way to less democracy and openness in the field. He points to the proprietary restrictions resulting from “closed” intellectual property as an example of legal risk and uncertainty. The challenge of course for those like Torrance who might wish this technology to be “open” to others is that synthetic forms are not “natural.” By definition as he concedes, “synthetic DNA sequences are likely more easily patentable and copyrightable than are DNA sequences derived from natural sources.”<sup>15</sup> Torrance ultimately comes to the conclusion that runs through this special issue: collaboration, cooperation, and new legal frameworks must be developed to govern the legal relationships between biotech developers and the contributors and users they serve.

#### CONCLUSION

In deciding to host a special issue dedicated to the scholarship of “*rising stars*” my colleagues and I reflected on the importance and value of elevating voices that deserve a platform. These authors contribute to a broad and rich literature at the intersections of law, medicine, science, and technology. Their insights illuminate gaps in current legal regulation of biotechnologies, and yet offer creative, innovative frameworks for addressing 21st century challenges at the heart of law and science.

Their works remind us that at the important intersection of law, science, and technological pioneering, social responsibility and accountability to the public must not be lost or bartered away. And with scientific achievements come responsibilities—sometimes unanticipated. These scholars’ nuanced approaches to challenging issues at the intersections will provide for an enriched and engaging dialogue for years to come.

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15. Andrew W. Torrance, *Synthesizing Law for Synthetic Biology*, 11 MINN. J. L. SCI. & TECH. 629, 664 (2010).