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## ***DEDICATORY ESSAY***

### **ADVENTURES WITH LORI ANDREWS**

*George J. Annas\**

The subtitle of Lori Andrew's autobiographical *The Clone Age* is "Adventures in the New World of Reproductive Technology."<sup>1</sup> This may seem an odd characterization of the life of a legal scholar, but adventures is just right to chronicle the life of this academic legal activist. Lori's legal adventures began at Yale Law School and continue in Chicago, where she was a researcher at the American Bar Association for over a decade and is now professor of law at Chicago-Kent College of Law and Director of the Institute for Science, Law and Technology. Her adventures in health law can also be dated from the day she took her bar examination which was, perhaps not coincidentally, the same day the world's first "test-tube baby," Louise Brown, was born. The new reproductive technologies have not provided her only health law subject, nonetheless, the legal issues they have gestated have been the primary focus of her work. This area of health law even has a new name: "reprogenetics," denoting the marriage of reproductive technology and genetic technology.

Throughout her legal career, Lori has been involved in exotic litigation. At first, it was to enhance and protect the infertility industry, including a successful challenge to an Illinois statute that de facto prohibited IVF. More recently it has been to protect the interests of patients, such as an ongoing suit against a researcher and hospital for their restrictive patenting of the Canavan gene. In the lawsuit, she represents families who provided their DNA for the research. Lori has also done mainstream, foundational scholarly work that has been widely acclaimed even by conservative medical professionals. Two examples are illustrative of her

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1. LORI B. ANDREWS, *THE CLONE AGE: ADVENTURES IN THE NEW WORLD OF REPRODUCTIVE TECHNOLOGY* (1999).

contributions. The first is in the field of genetics. She was coeditor of the Institute of Medicine's 1994 path-breaking report entitled *Assessing Genetic Risks: Implications for Health and Social Policy*, which helped set the research and policy agenda for genetic testing for the past decade and which remains the single most authoritative text on legal and ethical issues involving genetic screening and testing.<sup>2</sup> Her personal views on these matters are well-articulated and solidly defended in her own 2001 book, *Future Perfect: Confronting Decisions About Genetics*.<sup>3</sup>

The second example is from the burgeoning field of patient safety. When the Institute of Medicine produced perhaps its best-known recent report on patient safety and medical errors, *To Error is Human: Building a Safer Health System*,<sup>4</sup> the Institute's Committee on Quality of Health Care in America relied heavily on an empirical study of medical errors conducted by Lori and her colleagues.<sup>5</sup> As the Committee notes in the report, her study

[O]f 1,047 patients admitted to two intensive care units and one surgical unit at a large teaching hospital, 480 (45.8 percent) were identified as having had an adverse event, where adverse event was defined as 'situations in which an inappropriate decision was made when, at the time, an appropriate alternative could have been chosen.' For 185 patients (17.7 percent), the adverse event was serious, producing disability or death. The likelihood of experiencing an adverse event increased about six percent for each day of hospital stay.<sup>6</sup>

The Andrews study, the only prospective study of medical errors in the literature, showed that "adverse events" are much more common than most physicians and patients think, and also that other studies were likely to have underestimated them because they set too high a threshold for harm, too high a threshold for preventability, and included only errors that were documented in the medical record.<sup>7</sup> The policy implications, that

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2. Committee on Assessing Genetic Risks, Institute of Medicine, *ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY* (Lori B. Andrews, Jane E. Fullarton, Neil A. Holtzman, & Arno G. Motulsky, eds., 1994).

3. LORI B. ANDREWS, *FUTURE PERFECT: CONFRONTING DECISIONS ABOUT GENETICS* (2001).

4. Committee on Quality of Health Care in America, Institute of Medicine, *TO ERR IS HUMAN: BUILDING A SAFER HEALTH SYSTEM* (Linda T. Kohn, Janet M. Corrigan & Molly S. Donaldson, eds., 1999).

5. Lori B. Andrews, Carol Stocking, Thomas Krizek, et al., *An Alternative Strategy for Studying Adverse Events in Medical Care*, 349 *Lancet* 309 (1997).

6. *TO ERR IS HUMAN*, *supra* note 4 at 26.

7. *Id.*

medical errors are very frequent and that we must significantly reduce them to protect the lives and health of patients, are obvious.

Given Lori's reputation not only among her peers (who presented her with the Jay Healey Health Law Teachers Award in 2002), but among physicians and genetic researchers as well, it is not surprising that in 1995, when Nancy Wexler's five-year term ended, she was elected only the second chair of the ELSI (ethical, legal and social implications) Working Group of the Human Genome Project. Every year brings new ethical and legal controversies to genetics, and the ELSI Working Group was meant to anticipate them, analyze them and devise strategies for confronting them. What Lori did not know, but was about to learn, is that the job of the ELSI working group had been quietly transformed from critical thinker to cheerleader by the new head of the NIH Genome Center, Dr. Francis Collins. In her words:

As the months passed, I noticed a disturbing trend. The ELSI Working Group was given no budget of its own; instead we had to ask Collins and his staff for funding. Every time we planned an activity that might lead to more people getting genetic tests or participating in genetic research—such as protecting genetic privacy—we were given a blank check. But each time we planned an activity that called into question the power of genetic testing—such as a study of the problems of using genetics to predict intelligence, criminality, or certain psychiatric disorders—we were told that the Genome Center didn't have enough money to fund it.<sup>8</sup>

Worse than that, when it became apparent that even the NIH and the Department of Energy, the cosponsors of the ELSI Working Group, did not want to hear from ELSI about their own internal ethical conduct, Lori resigned (in February 1996). Resignation was unprecedented, and she remains the only person ever to resign as the chair of a major federal bioethics panel. Her resignation was a loud and clear statement that the emperor had no clothes, and that no one outside NIH could any longer take the group seriously as an independent ethical voice. James Watson, the first head of the Genome Project who had always taken credit for forming the ELSI Working Group, later explained publicly that as far as he was concerned the group was always meant to act as ethical cover for the project, and never to do serious ethical or legal work. In Watson's words, "I wanted a group that would talk and talk and never get anything done, and if they did do something, I wanted them to get it wrong. I

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8. THE CLONE AGE, *supra* note 1 at 195.

wanted as its head Shirley Temple Black.”<sup>9</sup> With Lori neither Watson nor Collins got their wish. Instead they got that all-too-rare academic who was willing to stand up to scientific and government power and say, “I won’t play your game by your self-serving rules.”

Most recently Lori has found herself in the middle of perhaps the two most contentious contemporary issues in international health law and bioethics: the patenting of human genes, and human cloning. In neither is she bashful. On patenting genes she persuasively and concisely summarizes her position as follows:

In my view, the decision to allow patents on human genes was inappropriate, both legally and as a matter of sound policy. The useful properties of a gene’s sequence...are not ones that scientists have invented, but instead are natural, inherent properties of the genes themselves. Moreover, in my opinion, gene patents do not meet the criteria of nonobviousness, because, through in silico analysis, the function of human genes can now be predicted on the basis of their homology to other genes. In addition, as a matter of policy, human nucleotide sequences should not be patentable, even if their function is known, because such scientific information should be available to all.<sup>10</sup>

As to human cloning, I have recently had the pleasure of working with her on a draft of an international treaty to outlaw not only reproductive cloning (there is universal agreement from the countries of the world on this), but also attempts to alter the genetic characteristics of human embryos (to produce inheritable alterations). Lori’s work in this field has been informed not only by science and public policy, but also by her interactions with the world’s would-be cloners. Richard Seed, the Chicago physicist turned cloning promoter, for example, announced his intention to clone to the world at a conference Lori chaired at Chicago-Kent Law School. And when the head of his own religion, known as Rael, announced that little, green extraterrestrials had told him it was his job to develop human cloning on earth, Lori went to Canada to interview him.

She met with Rael and his science director, Brigitte Bosselier at the UFO Café in UFOland, a Raelian theme park. As Lori describes the scene: “We are sitting at a table with a plastic tablecloth with a design of pumpkins, artichokes and corn. The vaguely Halloween motif of the tablecloth captures the spirit of the meeting. Brigitte Bosselier is dressed

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9. *Id.* at 206.

10. Lori B. Andrews, *Genes and Patent Policy: Rethinking Intellectual Property Rights*, 3 *NATURE REV. GENETICS* 803, 803 (2002).

like Cleopatra. Rael is dressed in a white Elvis jumpsuit.” Lunatic false prophet fantasy of course, but as she explores the themepark’s twenty-six foot tall replica of DNA in a room shaped like a human cell, Lori muses, “I am struck by how everything, except the flying saucer itself, looks like part of the educational material from the Human Genome Project.”<sup>11</sup> Her observation prompts me to make another: would-be human cloners have so far succeeded only in cloning press conferences, and would-be creators of genetic-based medicines have so far succeeded only in patenting gene sequences. Hype springs eternal.

Meanwhile, back on the planet earth, Lori and I have suggested language for a proposed international “Convention on the Preservation of the Human Species” that would outlaw all efforts to initiate a pregnancy by using either intentionally modified genetic material or human replication cloning.<sup>12</sup> This treaty, we believe, would be a critical first step toward developing a global mechanism to assess and control all potentially devastating new biotechnologies - from xenografts to novel organisms to nanotechnologies, technologies that could threaten the survival of the human species. The United Nations is currently locked in a debate about whether to outlaw asexual reproductive cloning (sometimes called “baby-making cloning”) only or to outlaw research cloning (the making of cloned human embryos to produce stem cells for potentially therapeutic uses) as well. The issue of inheritable genetic alterations has yet to be addressed directly at the UN, but will have to be, and ultimately for the same reasons.

Banning human reproductive cloning is an ethically defensible and legally-enforceable line to draw that can both permit legitimate medical research and prevent a quick slide to a posthuman future:

...these interventions would require massive dangerous and unethical human experimentation, cloning would inevitably be bad for the resulting children by restricting their right to an ‘open future,’ cloning would lead to a new eugenics movement for ‘designer children’ (because if an individual could select the entire genome of their future child, it would seem impossible to prohibit individuals from choosing one or more specific genetic characteristics of their future children), and it would likely lead

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11. THE CLONE AGE, *supra* note 1, at 242.

12. George J. Annas, Lori B. Andrews & Rosario M. Isasi, *Protecting the Endangered Human: Toward an International Treaty Prohibiting Cloning and Inheritable Alterations*, 28 AM. J. LAW & MED. 151 (2002).

to the creation of a new species or subspecies of humans, sometimes called the 'posthuman.'<sup>13</sup>

Lori ends *The Clone Age* with a meditation on a speech she gave in Dubai on cloning to a group of armed Muslims who ultimately decided it was OK to clone men. As she reflects on their stance, she contemplates cloning from the perspective of her life of working on the legal aspects of the new reproductive technologies, and concludes that cloning is a good place to draw the line, for society to reverse the burden of proof and finally require the scientists to provide reasons why what they want to do is good for society, and how its benefits can be maximized and its harms minimized before they proceed. In her words, "Perhaps the main objection I had to cloning was it replicates everything that was troubling about reproductive technologies: excessive commercialization, reckless experimentation on women, procedures undertaken without consent, unmonitored physical and psychological risks." She continues, apologizing for the support she has provided to the infertility industry in the past, "My speech at Dubai was a mea culpa. I had helped make reproductive technologists invincible, and facing human cloning was like greeting Frankenstein's monster for the first time. The creation had gone amok. I needed to draw the line here to atone."<sup>14</sup>

Catholics, of course, understand confession and penance. Readers of Lori's wide-ranging work can decide for themselves if atonement is indicated. In my own view no apology is necessary. Instead, praise for a human rights champion who has entered the arena as an experienced and wiser adventurer is in order—as is dedicating this issue of the *Journal of Contemporary Health Law and Policy* to her.

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13. *Id.* at 161-62.

14. *THE CLONE AGE*, *supra* note 1, at 258.