



the gene queen

IN THE BRAVE NEW WORLD OF CLONING, GENETIC TESTING AND STEM CELL EXPERIMENTATION, LORI ANDREWS IS NOT ABOUT TO LET TECHNOLOGY TRIUMPH OVER ETHICS **BY STEPHANIE B. GOLDBERG**

Not long ago, Lori Andrews infuriated a group of ticket agents at O'Hare International Airport. But it wasn't your average case of air rage. Andrews, director of the Institute for Science, Law and Technology at the Illinois Institute of Technology, merely told them why she was flying to Washington, D.C.: to argue, at a briefing for senators and other insiders, that the current practice of patenting genes violates the public interest. Do the agents know, Andrews asked, that if they were tested for the breast cancer genes BRCA1 or BRCA2, their doctors would have to pay a substantial royalty to Myriad Genetics, Inc., the Salt Lake City company which, under U.S. patent law, "owns" the genes? This means that a lab test, which ordinarily would have cost \$50, now runs up to \$2,600, limiting who can take advantage of it.

"That's it," one indignant agent declares. "No more first-class upgrades for senators until they solve this issue."

"God, that's brilliant," Andrews remembers thinking, delighted at the response. As one of the nation's most

respected bioethicists—who has been wrestling with the moral and legal quandaries posed by gene patenting, cloning and embryonic stem-cell research long before they were front-page news—Andrews, 49, is eager for the public to play a greater role in shaping the policies that will affect their lives for years to come.

Her special gift is her uncanny ability to pare complex issues down to size and make audiences feel as if they're chatting with a good friend, rather than a celebrated academic. Identified as a savant in grade school, Andrews, the daughter of a pharmacist and a housewife, was writing for *Teen*, *American Girl* and other national magazines by the time she graduated from high school in Downers Grove, a Chicago suburb. In college, she began studying informed consent and the budding patients' rights movement after a family member became seriously ill; shortly after graduating from Yale Law School in 1978, she moved on to the ethics of surrogacy and test-tube babies, garnering speaking invitations at international conferences when she was in her mid-

twenties. By the time the Baby M lawsuit erupted in 1986, she was in every reporter's Rolodex.

Appearances on *Oprah*, *Today* and *60 Minutes* have only increased her renown, and she's now the "who ya gonna call" person for questions the law books don't answer. There was the hospital that sought her guidance when the parents, wives and girlfriends of six different comatose men demanded to harvest their sperm; or the fertility clinic that wondered if it was free to sell 300 unclaimed frozen embryos to a biotech company. Others seem to confuse her with Ann Landers, such as the woman who recently left Andrews a message about reuniting with the daughter she had given up for adoption 20 years ago. Her question: Did Andrews think it was okay to ask the daughter to donate an egg or two so she could bear a late-life child? (Wisely, Andrews declined to answer.)

Andrews fields these numerous inquiries from her office at the Chicago-Kent College of Law, where she's been a full-time professor for eight years. Petite and blonde, with classic features,

she appears on-camera as aristocratic and self-assured, the fearless female lawyer Hollywood has revered in movies like *The Jagged Edge* and *The Accused*. Off-camera, however, you encounter a very different Andrews: warm, outgoing, self-effacing, giggly and indefatigable; a bundle of nervous energy for whom life is an intellectual feast.

such as the U.N.'s World Health Organization or the Ministers of Science of the G-8 nations, it's gratis. When she helps strategize a patients' rights lawsuit, it's pro bono.

"Virtually all my income comes from teaching and writing," says Andrews, the author of nine books. In her most recent publication, *Body Bazaar: The*

physicals or substance-abuse testing. "In large part, I see my role as getting the information out there," Andrews says. "I don't see myself as the country's moral guardian—just someone who can frame the issues so people can make their own decisions."

Though concern for individual rights is the guiding principle underlying her work, predicting where Andrews will stand on any given issue isn't easy. She urges caution with stem-cell research even though, as a pro-choice feminist, she doesn't believe that embryos should enjoy unconditional protection. In her view, the fact that the embryos in question are to be destroyed anyway doesn't justify a lab doing whatever it wants with them. "There at least should be good rules about getting consent from the couple donating the embryo and making sure that the research being done is important," says Andrews. "Over the past twenty years, I've been told that we're on the verge of some major cure with gene therapy that never materializes."

She's critical, however, of President

"So much of the joy of parenting comes from the surprises. Trying to program traits in children doesn't necessarily lead to the best characteristics"

Andrews stands out in the field of bioethical policy-making in that her only interest is the public interest. While some would give the biomedical establishment a blank check, Andrews holds them strictly accountable. She's not aligned with either religious groups or the influential, well-funded biotech lobby, the primary drivers of debate in cloning and stem-cell research. When she consults with governmental groups

Market for Human Tissue in the Biotechnology Age (Crown Publishing Group, 2001), which she coauthored with Dorothy Nelkin, professor of law and sociology at New York University, she becomes a latter-day Paul Revere, warning of dangers already on our doorstep. She reports that an alarming 30 percent of large- and medium-sized companies already obtain genetic information about their employees via company

IS THAT HER FINAL ANSWER?

Traditionally, courts extend legal precedent to cover new situations, but the questions raised by biotechnology advances (What makes a woman a mother? Should life forms be patentable?) defy easy categorization. Yet, cases making their way through the system now will shape our notions of family, privacy and individual rights for centuries to come. We asked Lori Andrews to weigh in on some important cases, and how they might shape our brave new world:

THE CASE: An infertile couple has a baby with donated eggs and the husband's sperm and leaves five unused zygotes (a fertilized cell

that can grow into an embryo) in cold storage at the clinic. Some years later, the couple divorces and the woman wants to have one of the zygotes implanted. Her ex-husband wants them destroyed.

WHAT HAPPENED:

The court of appeals declined to declare either party owner of the zygotes and ruled that the couple must come to their own agreement.

WHAT ANDREWS

THINKS: "Increasingly, the court's definition of 'mother' extends beyond traditional blood ties. In a case where an infertile woman contracted with an egg donor and a surrogate to bear her child, a court held the infertile woman to be the

mother, because that was everyone's intent at the beginning of the arrangement. In this instance, it should make no difference that the woman used donated eggs.

"However, even when embryos are created with the wife's own eggs, courts have generally given more weight to the ex-husband's desire not to reproduce than to the ex-wife's desire to carry the embryos to term. I feel that, before conception, couples should sign agreements about who will get custody of the embryos. With more than one hundred and fifty thousand frozen embryos in storage, as many as ►

Bush's recent announcement to limit federal funding of research to the 60 existing cell lines. "It's unlikely that all racial and ethnic groups are represented," Andrews says, which may limit what groups benefit from this publicly funded work. Worse, the decision confers a monopoly on a handful of institutions that own exclusive rights to the cell lines; it raises the possibility that these groups could charge a huge sum for whatever tests and treatments result.

She's fiercely opposed to cloning and has drafted guidelines to ban it, which became the blueprint for legislation introduced by Senator Ben Nighthorse Campbell (R-Colorado). (The House of Representatives passed a similar law in July, but the Senate version is stalled in committee.) Cloning is too dangerous, Andrews says, and plays havoc with concepts of identity and integrity.

"Right now, one third of the [cloned] animal offspring are dying, either shortly before or after birth," she says. "We certainly shouldn't be creating a situation that has such high risks for children. The psychological risks to the

IS THAT HER FINAL ANSWER? (continued)

twenty thousand may be the subject of disputes."

THE CASE: A group of parolees, residents and prisoners sued Massachusetts for taking DNA samples involuntarily for a police crime-lab database, claiming it violated their constitutional rights.

WHAT HAPPENED: The suit was dismissed. The court rejected the argument that taking DNA from a felon was an illegal search and seizure.

WHAT ANDREWS THINKS: "The Fourth Amendment protects people from unreasonable search and seizure (including blood tests) unless there is some evidence linking them to a crime. Yet states mandate taking DNA from all prisoners on the grounds that some of them might later commit other crimes. I side with a dissenting judge in a Virginia case who pointed out how this logic would allow police to enter a minority or poor neighborhood and search everyone just because the population as a whole has a higher crime rate than a rich, white neighborhood."

"Some politicians have suggested taking DNA from all of us at birth and storing it for use by the police. Yet because of laboratory errors, innocent people might be convicted of crimes."

And our most private genetic information would be kept in a government DNA bank, available to insurers, employers or others for genetic discrimination."

THE CASE: A railroad worker files a disability claim for carpal tunnel syndrome. He is asked to take a blood test. His wife, a nurse, becomes suspicious. They learn that he and about 120 other employees filing for disability have been the subject of involuntary genetic testing. He files a complaint with the Equal Employment Opportunity Commission.

WHAT HAPPENED: The EEOC filed charges that the employer had violated the federal Americans with Disabilities Act, and the railroad settled.

WHAT ANDREWS THINKS: "New laws are needed to protect people against genetic discrimination. Already, insurers have denied coverage to healthy women on the grounds that they have a genetic propensity to breast cancer. Employers have secretly tested people, sometimes to claim that a workplace injury was due to the employee's faulty genes. In this case, the railroad backed off when challenged—but there is no specific law to prevent employers from

requiring genetic testing of workers."

THE CASE: Several animal rights groups sued the federal government to ban the patenting of animals implanted with cancer genes.

WHAT HAPPENED: The case was dismissed.

WHAT ANDREWS THINKS: "In my mind, living organisms should not be patentable. For most of its history, the patent office agreed. A 1980 U.S. Supreme Court decision, though, allowed the patenting of genetically engineered bacteria, because the inventor had created a living entity that didn't previously exist. This approach leads to absurd results.

American researchers, for example, filed a patent in Europe for mammals that have been genetically engineered to make pharmaceuticals in their breast milk—and they asked for patent rights covering women with the genes as well. That should be alarming—that someone, somewhere, may decide that human beings are patentable. It's gained enough momentum that at a recent meeting, the Intellectual Property Section of the American Bar Association put forth a resolution that that would prohibit patenting people; believe it or not, that generated controversy."

Amanda Urban. "She does things more quickly than normal human beings," says San Francisco lawyer Dennis Rioridan, who recalls Andrews plowing through several thousand pages of court transcripts in just two weeks while writing a biography on his client, Black Panther Johnny Spain. "It's not unusual to see her late in the afternoon helping her son with his homework, talking to a *New York Times* reporter and working on something she's written, her hand moving at breathtaking speed," adds former boss Bryant Garth of the American Bar Foundation in Chicago, where Andrews held a fellowship for more than a decade.

All who know her agree that her 13-year-old son, Christopher, is very much the center of her life. Andrews has a loose custody arrangement with her ex-husband, Clem, whom she met at Yale and with whom she remains good friends since their divorce seven years ago. He lives a couple of blocks away and accommodates her frequent trips overseas. Parenting has also given her insight into her work. "So much of the joy of parenting comes from the surprises. Trying to program traits in children doesn't lead to the best characteristics," says Andrews.

Now she's poised at a unique moment in her career, as Hollywood beckons. She's been working with Jonathan Shesstack, producer of *Air Force One* and other movies, to develop a television series based on her life. In August and September, they shopped the idea to various networks and are waiting to hear what happens. Andrews holds her own quite well in LaLa Land, says Shesstack. Adds Andrews: "It's incredibly odd to sit in a room and be talked about as if you weren't there. People would say, 'What can we do to make her more interesting?' and come up with things like tap dancing for a hobby."

Andrews has no time for hobbies. If the race to reclaim our designer genes ever slows, perhaps she'll have the space to pursue her one unrealized ambition. "I'd love to write a mystery novel," says Andrews. Whether it's on the printed page, in a test tube or outside the closed-door dealings of the Senate, Andrews loves a good mystery. ■

child of not having autonomy or an open future are more persuasive."

As Andrews ponders the mysteries of life, she's a bit of a mystery herself. How is she able to accomplish as much as she

does? At any given time, she's juggling as many as ten projects. "She's clearly one of the smartest people walking the face of the planet," says her powerhouse literary agent of nearly 15 years,