

An Introduction and Mission

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“Breaking Bioethics” is the newest section of *Cambridge Quarterly*. Twice each year these pages will feature a colloquium on a breaking issue in bioethics.

The Rationale

How unpredictable is American biomedicine.

Take reproduction. In 1997 sixty-three-year-old Arceli Keh fooled a California in vitro fertilization team about her age and suddenly emerged on the public scene when she gave birth to an infant. An American wire service writer broke the embargo on a *Nature* article about nuclear transplantation from a somatic sheep cell into an egg, and subsequent birth of a “clone.” The birth of that sheep was described in terms of “human cloning implications” by every reporter in the nation, and a feverish mob of producers chased down bioethicists for comments. A researcher whose work on gestating headless tadpoles was slated for publication talked with a BBC film crew about “spare parts” from headless human embryos, resulting in British legislation against “headless” human organ donors. A child was born from an egg that was frozen before it was fertilized, leading women’s magazines to suggest that young women bank their eggs. And to cap the year, a pro-life couple in Iowa used strong fertility medications, refused selective termination of their septuplet pregnancy, and beat impossible odds against successfully bearing seven children. Iowa bought the family a house, while other, slightly less fertile sextuplet parents complained that they had received no assistance with their \$1 million neonatal care bills. Americans marveled that none of these experiments were debated *before* they took place, and wondered how the flourishing imaginations of assisted reproduction had avoided regulation for so long. As happened with Quinlan, Cruzan, and Baby M, human need plus surprising new science made for urgent problems at the bedside and in the statehouse.

If much of bioethics is reflective and ethnographic, a new chunk today is also intense, temporal, and responsive. Fifteen years ago, bioethicists began to think about the importance of working with members of the media and government about formulating policy and educating the leaders of social institutions. Many philosophers and theologians, though, resisted the idea of “rapid response” bioethics. The archival record of bioethics shows how war has been waged over the idea of “public” ethics debate. After all, how effective are scholars, and particularly philosophers, at advancing or challenging complex, political agendas for health and science? Some bioethicists have become part of the instant-response, public debate about science and healthcare. Today the most conten-

tious issues in medicine are framed in “bioethics” language. Bioethicists write “next-day” Op-Ed responses to news stories for *The New York Times* and propose policy on prestigious commissions.

One thing is clear: bioethics is at a pivotal point in its development as an institution. Will the trend to publishing bioethics articles in clinical journals continue? How important is it to publish reflective, “bioethics for bioethicists” when so many others—at the bedside, in medical classrooms, in law schools, and in Washington—need to be engaged in conversation about pressing moral issues? Will bioethics increasingly be identified by those who mete out commentary for the news media, on the web, and on cable? Will “reports of the commission on bioethics” become the model for making the work of bioethics more public? Which of these should we prepare our bioethics graduate students to accomplish?

On the one hand, it takes time for good scholarship to emerge. The first-tier journals of bioethics, such as *Cambridge Quarterly of Healthcare Ethics*, must wait for reflective and scholarly research articles about questions in medicine and biomedical research. These, and scholarly books, are the defining literature of bioethics, and the coin of the realm. Much of the bioethics literature is published today by clinical journals, whose review cycles are much shorter and whose audiences are larger and more oriented to the bedside. Yet all agree that the scholarly bioethics literature is the place where bioethics peers interact and develop foundational frameworks and long-term research plans. The theoretical and methodical state of the art is negotiated in our bioethics literature. And in its core journals, bioethics struggles with its mission and goals.

On the other hand, the demand for instant-response bioethics is overwhelming. It is a matter of time before bioethics centers and faculty begin to cross over into print, radio, and television journalism; and conversely in the Master of Bioethics program at the University of Pennsylvania we have already had numerous applications from journalists interested in working the “bioethics beat.” In 1997, more than 1 million people from around the world visited the Penn Internet Bioethics Project at www.med.upenn.edu/bioethics. More than 10,000 newspaper articles were written about cloning and assisted reproduction, and virtually everyone in bioethics succumbed to the call of the camera, providing commentary on Jack Kevorkian, the Supreme Court’s rulings on assisted suicide, ethics in managed care, new genetic tests, patenting of genes. The change in media markets is palpable. Where 10 years ago a breaking health story might have taken weeks in “translation” and received commentary only belatedly in philosophical literature, today health and science news is provided on web sites, 24-hour cable news, and even special PBS programming. Scientists receive media training, and with good reason: Ian Wilmut appeared on 142 television programs in 18 straight hours of coverage of his cloning experiment.

The problem, of course, is in finding the middle ground for the exercise of the virtues of bioethics. Bioethics by commission has made some inroads in policy, but misses the importance of public education and grassroots conversation. Bioethics by media can be a dangerous beast, not for the careless or meek. Media coverage can distort as much as it reveals; at its best it provokes polarized political debate and at its worst it can scare patients, families, and political interest groups into odd or luddite fears of medicine and research.

At the same time, articles about new issues that arrive on the scene months after bad policy is enacted do not help either. Reluctance by bioethics faculty to

talk with ordinary people in ordinary fora, like churches, high schools, and television, is more damaging than excessive hype. As a result of bioethics' emphasis on long-term, high-pitch scholarship and national commissions, many bioethics centers are totally unknown by the churches, schools, and other institutions that actually cope with bioethics issues. Bioethics magazines and news programs have been proposed because of the vacuum in public discussion about the foundational issues that underlie bioethics scandal. How can ordinary families decide about cloning if they haven't thought about the values that undergird our social values about what kinds of family arrangements "work?" How are rabbis to talk about patenting of genes if they have not been engaged in discussion about the meaning of genes?

The Mission

"Breaking Bioethics" is an attempt to provide one kind of bridge between scholarship about new issues and those who need the scholarship outside bioethics. In this section, bioethics faculty and researchers will react to a current and breaking issue at a deep level. However, at the same time the pitch of the section will be to ordinary readers from the real world. Our goal will be to reach those affected by new medical problems, with short reflective articles.

A synopsis of each "Breaking Bioethics" will also be available through the website of MS-NBC, msnbc.com, and will be discussed on the monthly MSNBC Health At Issue series. Notice of each new section will be made as well by the *Penn Bioethics* newsletter, circulating free internationally to leaders in policy and the media.

Take One

In the first edition of "Breaking Bioethics," several scholars react to the emerging issue of human gene patents in the first comprehensive collection of essays about the ethics of patenting human genes. The focus is on gene patenting, but more specifically on the kind of gene patents that is most interesting for the future of gene mapping: so-called disease gene patents. In the section, both the pro- and anti-patent cases are reflected, but perhaps more importantly, the issue of what a patent might *mean* is discussed at a basic level. Intended for a teaching or group reflection setting, this collection of essays reflects genuine disagreement about a very important and controversial issue. In future sections we will discuss the enhancement of human capacities, and other breaking issues in bioethics.