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Global Bioethics

Hopes, Fears, and New Voices

As science increasingly crosses borders, so do the implications of deeply personal health sciences. Can new voices help in bioethical dialogue?

During the 1990s, James Grifo, a physician and researcher at New York University, had been working to develop a technique to help treat certain kinds of infertility. Although in vitro fertilization (IVF) treatments had been successful for many of his patients, IVF could not help women whose eggs were genetically sound and could be fertilized, but were not viable enough to grow into a healthy embryo. In such cases, Grifo imagined it might be possible to remove the nucleus from a donor egg from a healthy woman, replace it with the gene-carrying nucleus taken from the patient's egg, and then implant the reconstructed egg into the patient's uterus where it would continue to develop. Because the implanted egg would retain the mother's DNA, she would give birth to a biologically related child.

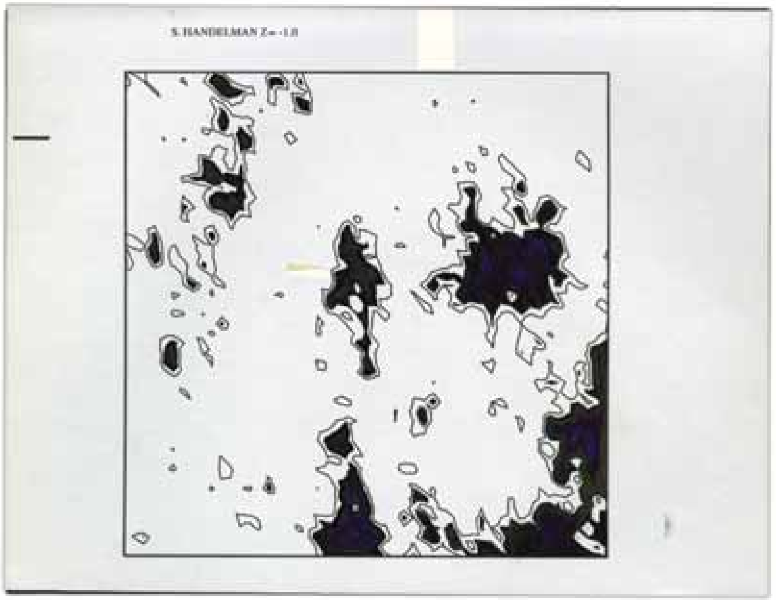
Although the idea had never been tested, it gave hope to one of Grifo's patients who desperately wanted a biologically related child. Willing to gamble on this coveted goal, she gave Grifo half a million dollars over 10 years to work on the technique.

It was a basic human desire combined with unfortunate circumstances, but also with the extraordinary potential that scientific research seemed to offer. These are common ingredients in questions of bioethics. Health science research is driven by many kinds of desires and is often coupled with a sense of urgency. Previously unimagined techniques seem to put distant hopes suddenly within reach.

Complexities arise

Grifo first conducted a series of experiments in mice. Once he had perfected the technique of nuclear transfer between eggs, he wanted to see if the eggs could produce viable offspring. His team implanted the eggs in mice. It worked. Several litters of healthy baby mice were born.

The time felt right to try the technique in humans. Grifo and his team had become adept at the precise and fastidious



BENOÎT MANDELBROT AND SIGMUND HANDELMAN (PROGRAMMER), *Islands*, Handcolored computer-generated print 1975.

technique of nuclear transfer, and his patient, having waited while the technique was developed and perfected, was getting older. The team tried the experiment in five patients, including the woman who had funded the research.

It failed. "The eggs made with nuclear transfer fertilized and made embryos, but no one got pregnant," Grifo explained. The eggs, it seemed, were too immature.

At New York University, Grifo is the director of the Division of Reproductive Endocrinology, the director of the Fertility Center Program, and a professor of Obstetrics and Gynecology. His line of work meets a real demand. According to the Centers for Disease Control and Prevention, nearly 7.4 million U.S. women between the ages of 15 and 44, or roughly 12% of this demographic group, have sought treatment or services for infertility. Behind these statistics are individuals and families struggling with difficult news and asking about what new treatments might become available. Although most women lack the wealth and willingness to go to such extreme lengths as Grifo's patient did, infertility evokes deep human emotions, desires, and hopes. It also brings out deep fears.

So do some new scientific procedures, especially when they relate to creating, sustaining, or ending human life. And here bioethics gets complicated. Here, profound individual experiences of hope, desire, and fear meet with disparate societal hopes and fears, ethical questions, and a fair measure of the unknown.

To many people, bioethics sounds like an abstract idea, something official panels and committees discuss. But bioethical problems start with a story, or usually many stories, often about people having hope despite long odds. Hope to overcome a disease, to conceive, to heal from an injury. And when that story has conflict, as all good stories do, the conflict often comes in the form of fear: fear of the unknown, fear of cultural change, fear of technology, fear of ethical or moral slippery slopes.

Grifo and his team ran headfirst into that fear. One day in 2001, Grifo received a call from Susan Blumenthal, who was then the U.S. Assistant Surgeon General.

"I'll tell you exactly what she said," Grifo recalls: "'What the hell do you think you're doing up there?' So I explained the history, the fact that we had IRB approval for all aspects of it. And she said, 'You need to do this in monkeys first.' Well, monkey IVF is way behind human IVF, and I don't have any monkeys who want it."

IRB approval—approval by an institutional review board—is a cornerstone of ethical and responsible research. Before any research can be done on animals or humans, the institution (New York University in this case) –must conduct a review of the proposed research to ensure that it conforms to ethical standards. Grifo's research had received such approval every step of the way.

A week after the telephone call, Grifo received a letter from the U.S. Food and Drug Administration (FDA) telling him that he had to file a new drug application. He was shocked. "We weren't doing drug research," he says. "The FDA doesn't regulate this kind of research. They dared me to keep doing it." In fact, in 2001, the FDA did claim jurisdiction over nuclear transfer research. It had become clear that Grifo would have a hard time continuing this research in the United States.

Here, bioethics gets even more complicated: Science and bioethics are globalizing. Researchers collaborate across universities, countries, continents, and cultures. Worldwide, people such as Grifo's patient face health challenges and raise hopes that drive research. Lawmakers in different countries are making different decisions about the ethics of such research. As research travels, it runs into different ethical and legal boundaries and also potentially transgresses or circumvents those boundaries. This can feed xenophobic stereotypes in which some countries are depicted as overly permissive, as fundamentally unethical. But it has been amply demonstrated that stereotypes often obscure more than they reveal.

Scene shift

At the time of Grifo's telephone call from the FDA, John Zhang, now a well-known IVF physician in New York, was a senior research fellow in training with Grifo. Zhang had colleagues in China, and Grifo and Zhang decided to offer the researchers in China the chance to continue the work. None of them anticipated what would happen next.

On October 14, 2003, major media outlets—including *The New York Times* and *The Washington Post*––reported that a research team at Sun Yat-sen University in Guangzhou, China, had successfully impregnated a woman using eggs made by nuclear transfer. This was the team, led by Guanglun Zhuang, to which Grifo and Zhang had given their research. Although no baby was born––the three fetuses that developed from implanted eggs were delivered too early to thrive––the research nonetheless suggested that the technique was sound. Grifo recounts that the lack of success was due to obstetrical problems rather than problems with the procedure itself. "It worked," he says emphatically.

The media focused on several concerns. One was that since human eggs contain a small energy center called a mitochondrion, which exists outside the nucleus and has its own tiny amount of DNA inherited solely from the woman who produced the egg, children born of this technique could be said to have three genetic parents: the egg donor, the woman who carried the implanted egg to term, and the man whose sperm was used to fertilize the egg. Also, concerns were expressed that research using the nuclear transfer technique was a step toward genetic engineering of human beings and human cloning. A third concern was that the technique, still experimental, might pose unknown risks to the safety of the mother and any children. Media reports highlighted the newness and riskiness of the technique, framing it as a story of questionable scientists and questionable ethics. They asked, ought we to do this kind of work? Is it too risky?

Grifo was shocked at the emergent controversy. For him, the media reports fueled public outrage and misunderstanding. He is adamant that the procedure does not constitute cloning. "Cloning is making a copy of a human being who already exists," he said in a 2003 interview with *The New York Times*. "This is nuclear transfer, one element of cloning. It allows a couple to have their genetic baby, not a clone. They shouldn't even be discussed in the same sentence."

It is important here to clarify the distinction between reproductive and therapeutic cloning. Mention of human cloning tends to evoke the image of an identical person, but this has not yet been shown to be possible in humans. Therapeutic cloning, which is the aim of most human embryonic stem cell research, involves the production of an embryo with identical DNA to the patient from which stem cells are then harvested and used––hopefully––to treat the patient's condition without risk of an immune reaction. Reproductive cloning has the intention of creating a genetically identical human being and is banned in most countries. Thus the debate about the use of human embryos for stem cell research involves therapeutic cloning but not reproductive cloning, even though they share techniques.

To Grifo, the issues raised in the mainstream press represented a misunderstanding of the science, the kind of misunderstanding that is often at the center of bioethical debate. The researchers saw their work as straightforward and in the interest of patients. But other people had more visceral reactions, along with complex questions about how, when, and under what conditions scientists ought to intervene, for instance, in matters such as human reproduction.

It is also hard to separate politics, economics, and culture from the controversy. Individual experiences, cultural elements, national politics, economic competition, and global politics all shape bioethics together, and each of those is somewhat influenced by, and also influences, media portrayals.

Viewing events in retrospect, Grifo says he would never have published anything until the technique produced a baby. He knows it makes a difference when and how people hear about a technique in the media. Recalling the first attempts in the 1970s to produce a baby via IVF, he notes that the first was an ectopic pregnancy and the second a miscarriage. If the press had reported on these results in today's environment, he reasons, government regulators would have stepped in and researchers would not have been allowed to make the progress that they have in IVF. By now, more than 3 million babies have been born through IVF.

Traveling science, traveling bioethics

Bioethics gets even more complicated when deeply personal disruptions become entangled with national, international, or indeed global considerations. Bioethics frequently addresses questions of global significance that consider human flourishing and risk on a grand scale. But the experiences that it draws and deliberates on are often, at their core, deeply personal: bearing a child, watching a loved one suffer, living with a devastating disease, facing death.

The nuclear transfer experiment was, at its core, about real women with all the personal challenges that go along with pregnancy and infertility. It was a familiar story: A woman wanted to have a baby of her own and had fertility problems. She wanted the baby to be genetically related to her, not to the egg donor. This mattered to her personally, not as an abstract and theoretical question of ethics. It also mattered to the women who participated in the China study.

To Grifo, the research is ethical in that it answers to a serious problem; it is the regulations that are not ethical. Of the patients struggling with fertility problems, "I sit here and listen to them weep," he told *The Wall Street Journal*. "That is powerful. And not one person writing the laws understands that."

For Grifo and Zhuang, the tears and hopes made transnational partnership worthwhile. But if the media storm that followed was hard to foresee, so perhaps were the stereotypes embedded in that storm.

Wild East?

Reproductive biomedical research is not just about the ethics of conception; it is also about the ethics of misconception. When the West generates stereotypes about Asia, there are personal repercussions for Asian researchers, for the global research community and its supporters, and for people wanting to bear children and manage disease. The way people in the United States perceive Asia has implications for the future, for Asia, for the United States, for science, and for questions of global bioethics.

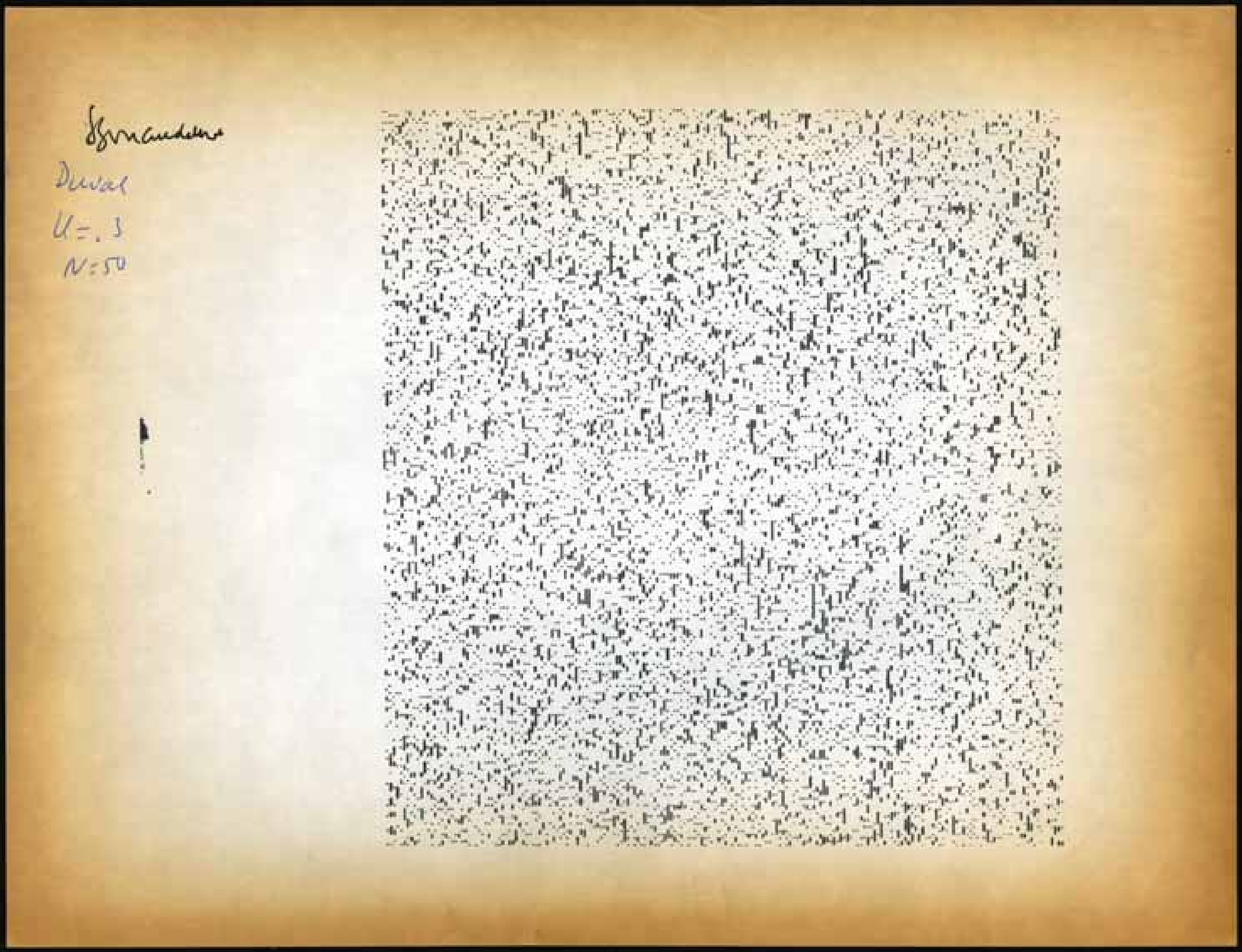
How do national boundaries matter as scientific research becomes increasingly global? As the Grifo case illustrated, it is hard enough within a single country to agree on bioethical questions. As researchers and research increasingly cross national boundaries, and because biological research increasingly has implications for all of humanity, people are asking questions about how it might be possible to establish international standards of bioethics in light of cultural differences and scientific competition.

For some people, the Grifo-Zhuang experiment smacked of ethical outsourcing. It gave rise to fears that Asia was like a new Wild West––or Wild East––of unfettered, unethical scientific practices. A *Wall Street Journal* report in 2003 on the work pointed to the light enforcement of regulations governing fertility clinics in China, "making China a growing haven for freewheeling research into reproductive medicine and cutting-edge genetics." Jeffrey Kahn, the director of the Center for Bioethics at the University of Minnesota, said in a 2003 *New York Times* interview that he sees this kind of transnational collaboration as a way of skirting ethical issues and regulations, "as an end run around oversight and restrictions within the United States." To the extent that bioethics is shaped by hope and fear, this is the face of the fear: fear of the unknown and often a xenophobic fear.

News representations of Chinese biotechnology at that time reflected such fear. Reports said that Chinese biologists had engaged in human cloning, that embryologists had transferred human cell nuclei into rabbit eggs, and that relatively little public debate was taking place. Such reports fueled an impassioned and fearful response in the United States. As a typical example, the *New Atlantis* journal ran an article in 2003 titled "Chinese Bioethics? 'Voluntary' Eugenics and the Prospects for Reform." The authors referred to recent experiments in China that "raise yet more troubling questions about the ethics of biotechnology in that still authoritarian country," and they concluded that "it is therefore a distinct possibility that the Chinese government will permit and perhaps secretly encourage the creation of cloned or genetically modified children for the 'good of society.' "

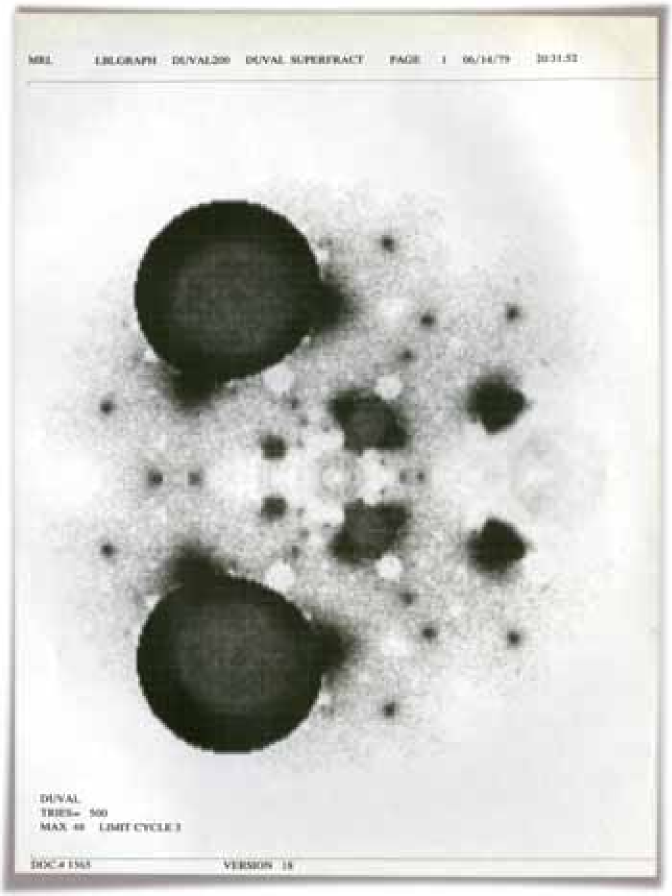
Such research projects do indeed merit serious attention. They should provoke intense scrutiny and ongoing public and governmental consideration wherever they are conducted. Although many of these same kinds of research projects were underway at Western sites, in the media these researchers were mainly characterized as rogue scientists who were seeking fame and fortune, or as marginalized "sects" or "cults"—in other words, as individuals rather than representatives of a country. But in discussions of Asia, and of China in particular, questions of bioethics were framed at the level of a people, culture, country, or region.

Bioethical institutions were developing in China even as these controversies were taking place. Ole Doering, a China specialist and philosopher, reports that a "new wave of infrastructure building to regulate and monitor biomedical activities in China took off in 1998." He, too, writes about ethical outsourcing, but from a different angle. Doering quotes a semi-official Chinese daily newspaper warning in 2003



Benoît Mandelbrot, *Investigations in the complex plane,* Possibly Harvard or IBM, Computer-generated thermographic print, ca. 1979-80.

that "we must be aware that some scientists from developed countries make use of the ignorance and eagerness of their colleagues in the developing countries to carry out experiments banned in their own nations." In this view, ethical resistance to the Grifo collaboration from a Chinese perspective might not so much question unscrupulous Chinese researchers, but unscrupulous and exploitative foreign, and implicitly Western, collaborators.



Benoît Mandelbrot and Mark Laff (programmer), *Investigations in the complex plane of cubic polynomials*, One from a series of over 150, IBM, Computer-generated print on photographic paper, 1979.

Racing ahead

The implications of the Grifo-Zhuang nuclear transfer aftermath reached far beyond fertility treatments and reproduction. The nuclear transfer technique was also seen as central to the promise of stem cell research. The hope was that if one could replace the nucleus of a human embryo with a nucleus from a patient's cell, then get it to develop for about a week or so, one could get stem cells with that patient's DNA. This meant that these stem cells could be used to potentially regenerate almost any kind of damaged tissue without prompting an immune response. The potential to treat formerly intractable conditions seemed close at hand.

Nuclear transfer thus holds high stakes and high potential in stem cell research. And stem cell research is frequently characterized as a race: among competing scientists, laboratories, and countries, as well as for cures, money, and fame. The phrase "stem cell race" abounds in the press. The phrase's popularity was fueled, in part, by the restrictions that President George W. Bush placed in 2001 on federal funding for human embryonic stem cell research. The restrictions limited federal funding to a few existing human embryonic stem cell lines, the so-called presidential lines.

Scientists quickly expressed concerns that the restrictions would threaten this field of medical science. Patients and families worried that treatments and cures would be delayed. Politicians and venture capitalists worried that their regions and investments would be hurt by restricted research funding. Fears and hopes continue to cycle through these bioethical debates.

Scientific globalization evokes images of international competition, every country trying to get ahead. Yet while many Westerners worried that Asian countries would race ahead, unfettered by research and ethical regulations, the inverse may actually be happening in some places. In countries where no regulations yet cover such practices as nuclear transfer or stem cell research, some researchers feel reluctant or even afraid to work in controversial fields without a green light from policymakers, ethicists, and the public. Indeed, policymakers in many countries are working hard to develop ethical research guidelines. Although some people still think of regulations as stifling research, a lack of formal guidelines could be worse, if this means that researchers are not certain what is culturally or legally permissible, now or later.

In China, regulators moved quickly in the aftermath of the Grifo-Zhuang nuclear transfer pregnancy story to ban the procedure. Despite China's quick response, stereotypes persist, as pointed out by Erica Jonlin, clinical research administrator and regulatory manager at the University of Washington Department of Medicine, whose daily work involves questions of ethics, research, and stem cells. On one hand, she says, "Scientists can collaborate. Scientists like to collaborate." But she says there remains a stereotype in the U.S. scientific community that scientists in China can do anything. In fact, if there ever were regulatory advantages to doing research in China, they've largely gone away. But the fear of unfettered Asian research continues.

Experiences in Taiwan

In some ways, China acted as a stand-in for a broader U.S. cultural fear about Asia, and East Asia in particular. Indeed, many people in Asian countries did see stem cell research, and biotechnology more generally, as a new hope, a way to catch up with the West on the global stage of science. They also saw it as a way to bolster their economies. Singapore developed Biopolis, a state-of-the-art biotech site based on the model of Silicon Valley and famous for recruiting high-level scientists from the West. South Korea developed a well-funded stem cell research laboratory at Seoul National University and seemed poised to become a global leader in stem cell research until a scandal involving its leader, Hwang Woo-suk, broke in late 2005.

Taiwan, too, announced in 2005 a national project to develop the country as "Biomedtech Island"––an Asian hub for biomedical technology. Underscoring the urgency, a minister of Taiwan's Science and Technology Advisory Group said in a 2005 report in *Taiwan News*, "We are under pressure of time to get the 'Taiwan––Biomedtech Island' plan going as soon as possible." Pointing out similar projects underway in China and Singapore, the official said Taiwan hoped to "compete well in the advanced biomedical fields and become the leader in the field in Asia." Stem cell research was an important part of this plan.

At Academia Sinica, Taiwan's most prestigious research institution, broad open spaces and rows of palm trees frame the state-of-the art science facilities. There, until recently, John Yu headed the stem cell research program. He and his wife, Alice Yu, left successful scientific careers in San Diego to help build Taiwan's biotech sector.

In practice, John Yu spends much of his time not at the laboratory bench but on the development of ethical research protocols. He founded the Taiwan Society for Stem Cell Research, which developed a scientific network and holds discussions on how best to regulate research. He served as Taiwan's representative at the International Society for Stem Cell Research and was a member of the task force that developed in 2006 the society's "Guidelines for the Conduct of Human Embryonic Stem Cell Research," a global standard for ethical stem cell practice.

He is a vocal critic of unregulated stem cell research and therapeutics. Work in Taiwan and elsewhere that is perceived as unethical risks resulting in public opprobrium not only for the individual researcher or physician, but also for the science itself. And although many people in the United States worried that an Asian lack of regulation and ethical constraint would create an atmosphere of unfettered and unethical research, in Taiwan, the opposite seemed to occur.

Consider the case of one young Taiwanese stem cell scientist. (Given the sensitivity of his position, he would rather not be named, so he will be called Dr. Li.) Beneath his soft-spoken and unassuming demeanor, Dr. Li exudes a passion for his work. For him, stem cell research has both deeply personal and national stakes. He grew up in Taiwan, then completed his education and training as a stem cell biologist in the United Kingdom and the United States. He began a family and was developing a promising career in the United States when he returned to Taiwan in 2004. Like John and Alice Yu, Dr. Li returned to help build biotech in his home country. "Maybe this will sound naïve," he says, "but originally I came back to Taiwan because I had this idea that it's my duty; that maybe I can help Taiwan a little bit on stem cell research."

In his previous work, Dr. Li had used dozens, perhaps hundreds, of human embryos. But in Taiwan, by 2007, when guidelines were still waiting for government authorization, he had not used a single one.

Instead, he helped to establish such guidelines and found himself in deep reflection about the ethicality of his own research. Rather than speeding up his research, the lack of clear policy in Taiwan slowed it down. It seemed that the established policies in the United Kingdom and the United States had enabled him to focus on his research, shielding him perhaps from deep ethical reflection of the type that now holds his attention. He also attributes this shift to more personal factors, such as his maturation and the birth of his first child. He recognized the potentiality that inheres in the human embryo. No longer seeing an embryo as just a research object, he came to see its potential, given just the right set of extremely contingent circumstances, to become someone's child. He understands the hopes that stem cell research inspires, and the fears, too.

Stem cell research has numerous risks. Individual scientists risk their reputations, careers, and even their freedom if they conduct work that is deemed unethical. Treatments are risky for patients. The science itself relies on public support. Researchers worry that hype and premature human treatment might ultimately diminish support. John Yu of Academia Sinica says this is the greatest worry for stem cell researchers: "We don't want society to expect too much in terms of what we can achieve now." He cites a U.S. survey which suggests that the general public's expectations about therapy developments from stem cells are much more optimistic than those of stem cell scientists. His concern is that hype and "unregulated" physicians will lead the public to expect too much too soon, thus setting the stage for the fragile support of stem cell research to be undermined when therapeutic production is slower.

Dr. Li is also concerned about public attitudes toward stem cell research, saying that "everybody that works in this field, they really want to know what is the public opinion." It is personal for him: "Myself, I want to know. I really want to know, what do they think about this." Although stem cell research is still not a major topic of public conversation in Taiwan, some insights about public attitudes may emerge from a study led by Shui-chuen Lee, a Confucian philosopher and bioethicist, and Duujian Tsai, a sociologist and community organizer. A team led by these two professors conducted surveys to identify public knowledge and public concerns about stem cell research.

As Dr. Li and John Yu know, it is not enough to progress scientifically; science has to be done carefully and correctly at every step. Taiwan became a full electoral democracy in 1996, after a 12-year transition period. Before, Taiwan was ruled under martial law for 38 years. So, domestically, public inclusion has become an important topic of governance––political and scientific. And internationally, public inclusion has become an important component of responsible scientific decisionmaking. It is not enough to have bioethical and research policies; increasingly, such policies have to both represent broad public consensus and conform to international standards.

The California experience

While people in Taiwan were taking surveys to assess their knowledge of and support for stem cell research, across the Pacific, Californians were showing their support at the ballot box. In a heavily funded campaign, proponents of Proposition 71, the California Stem Cell Research and Cures Initiative, asked the public to support stem cell research.

The campaign was successful. Passed in 2004, the initiative mandated state investment in stem cell research: $3 billion over 10 years. Proposition 71 represented a new kind of public engagement with science. With federal funding for most human embryonic stem cell research halted in 2001, California and several other states, including Connecticut, Illinois, New Jersey, New York, and Maryland, subsequently took it upon themselves to fund this type of research.

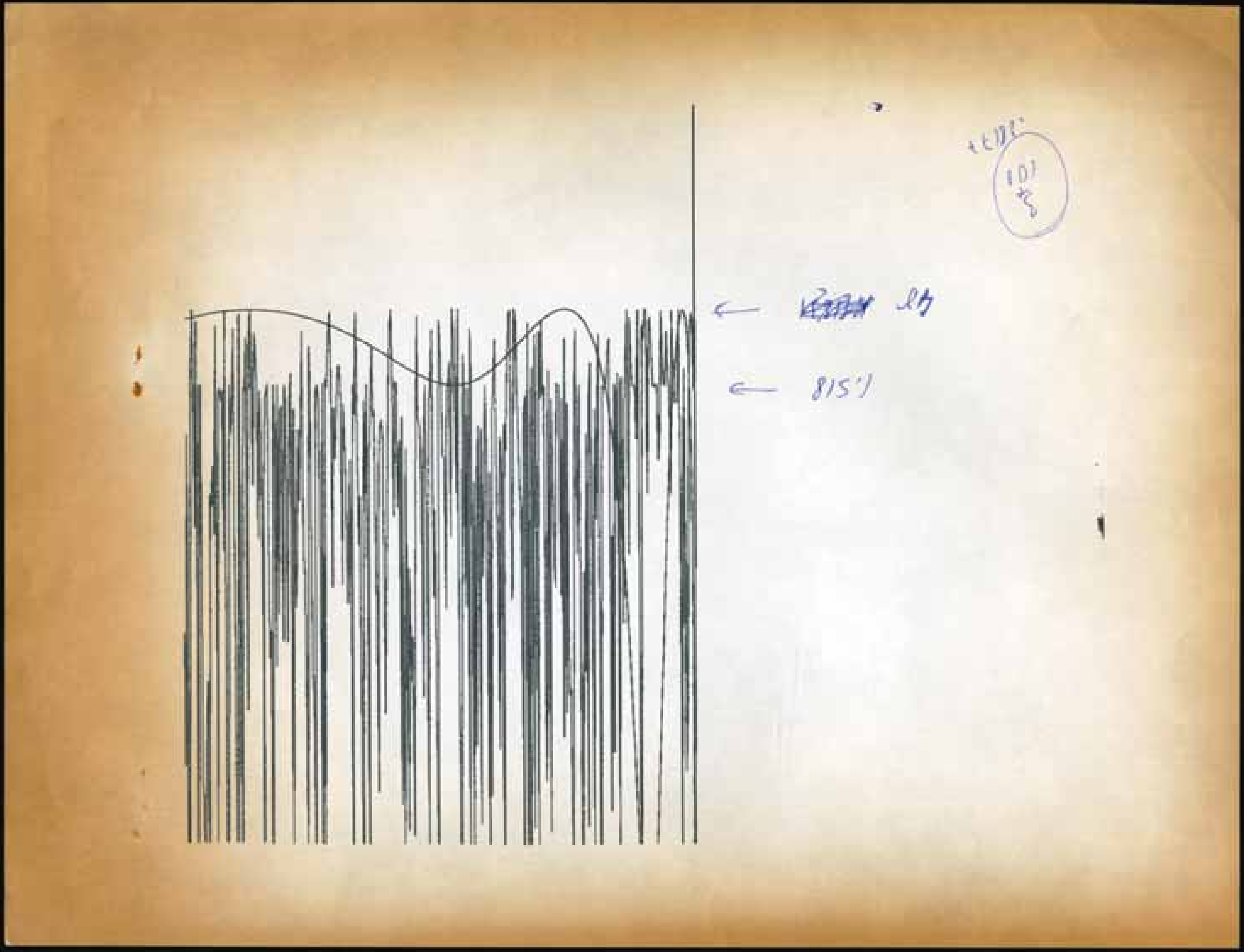
In California, many supporters saw a vote for Proposition 71 as a hopeful vote against President Bush and what they perceived as an anti-science, ideologically driven, and fear-building regime. They saw their vote as progressive, pro-science, and pro-cures, with real people's lives at stake. They also saw it as a more democratic, if risky, way to fund science. In California, public input has come to be seen as a necessary element in doing ethical science, in both research and its funding.

In a sense, then, bioethics has become explicitly context-specific. Classically, the field of ethics poses such questions as "What should I to do?" and "What constitutes the good life?" But when people encounter fast-changing biomedical technologies, these questions can be especially difficult to answer.

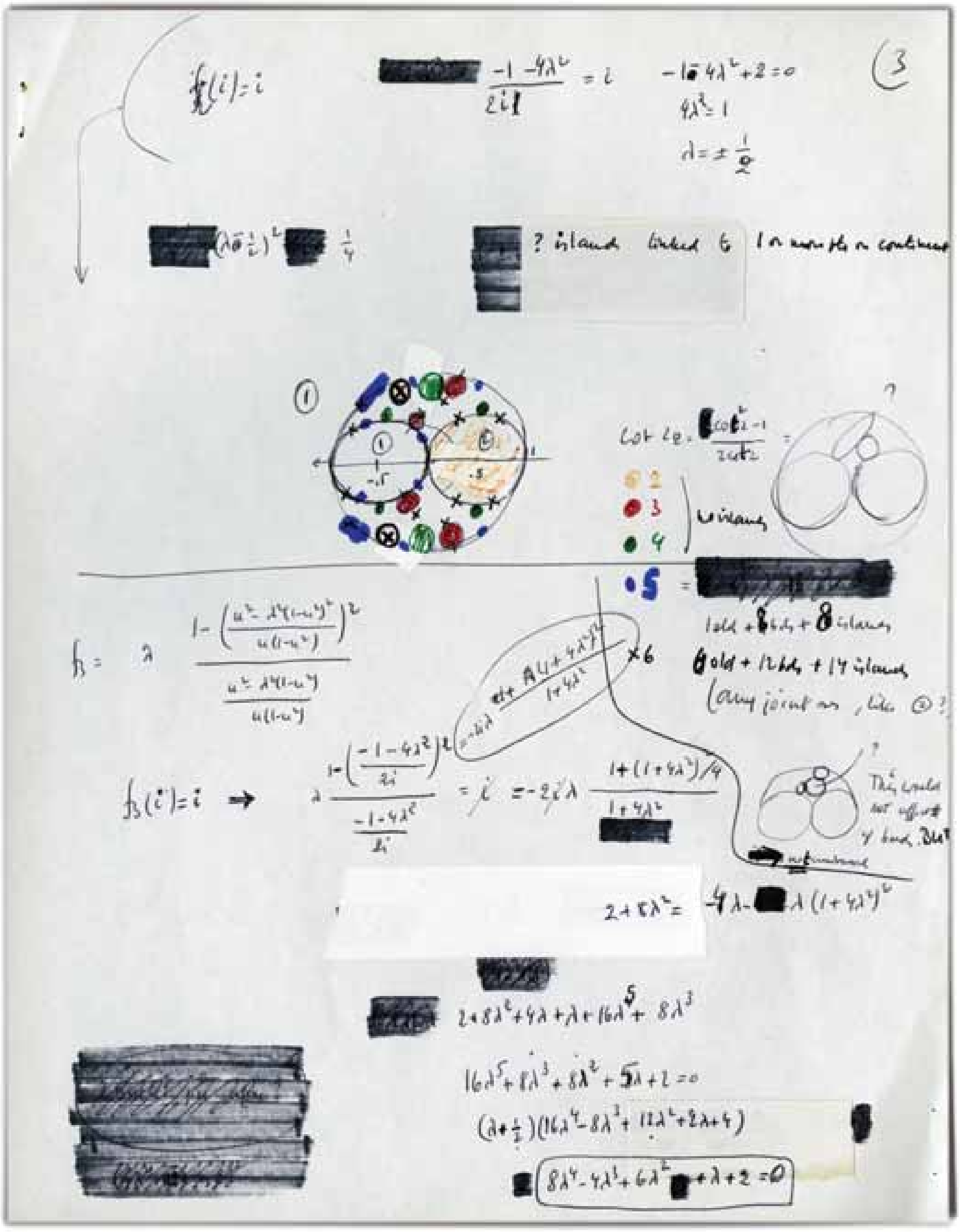
For Jeff Sheehy, advocacy is the answer, as witnessed by his active involvement in various aspects of HIV/AIDS work. He successfully established organ transplantation programs for people living with HIV in California and nationally. He is open about his own struggles in living with HIV. At a 2010 meeting of the California Institute for Regenerative Medicine (CIRM), he said, "For instance, I'm 53, so I'm here"—pointing to a graph of life expectancy for those living with HIV/AIDS—"and it's a real bet for me whether I'm going to make my five-year-old daughter's wedding, unless . . ."

In November 2004, Sheehy received a call from the leader of the California State Senate, John Burton, asking him to accept an appointment as a patient advocate to the governing board of CIRM, which was established by the passage of Proposition 71. Still on the board, he is also now director for communications at the University of California, San Francisco AIDS Research Institute.

Uniquely, CIRM included a mandate to include the state's diverse communities in every aspect of its decisionmaking process. As a result, these communities help in addressing a range of issues, such as determining which supply companies to use and setting mandates for preferential pricing for the state on any procedures and products to emerge from CIRM-funded research. Proposition 71 was seen to hold more than just the potential to produce cures for various



Benoît Mandelbrot, *Investigations in the complex plane,* Possibly Harvard or IBM, Computer-generated thermographic print, ca. 1979-80.



Benoît Mandelbrot, Scribbles on the topic of the Mandelbrot set and related to the question of the connectedness of the "islands", after 1980.

medical conditions; it was seen as a way for the state to gain a foothold in what held promise to become a burgeoning field of the biotech economy.

Writ more broadly, debates in the United States about stem cell research have mainly centered on human embryonic stem cell research and questions about the moral status of the human embryo. In a way unique to this country, the debates are shaped strongly by the divisive abortion issue. For some U.S. residents, the destruction of a human embryo on the research bench is equivalent to something like murder.

For Jeff Sheehy, this is a false argument. "It seems like the whole embryo argument here has been misunderstood," he says. He says that the embryos are not created for research, but are excess embryos "created to fulfill people who wanted to have children" using IVF. It would be better, he adds, for people who oppose the research to also support public funding of IVF, thereby reducing the strong financial incentive to create as many embryos as possible with each IVF cycle. This would, after all, reduce the overall number of embryos created.

Ultimately, Sheehy suggests, his voice rising slightly, the decision of whether to destroy these excess embryos, to donate them to science, or to give them to others seeking IVF should lie with the parents. "These are ethical choices for parents," he says. "They should have the autonomy as Americans and as parents."

Here, Sheehy appeals to the values of anti-paternalism, individual autonomy, and parental decisionmaking that he sees as hallmarks of the United States. He also brings up some broader questions: What kinds of matters should be private and what kinds should be public—and what kinds of things should be publicly funded? The ongoing health care debates and the recession have revealed much about the deep divisions that exist about such topics.

For countries, scientists, and patients, the stem cell race is afoot. Each group experiences a sense of urgency, but none more so than those of patients waiting and hoping for treatments and cures. Sheehy feels this acutely; he has seen his community devastated by HIV/AIDS and, after all, he hopes to make it to his daughter's wedding.

It is turning out that stem cells look like they may be able to cure HIV infection. In 2008, doctors in Berlin reported that a stem cell transplant had functionally cured a patient with HIV. In 2009, CIRM committed up to $20 million for a study to replicate the results. This would not have happened without Sheehy on the governing board. Many of the board's members thought that such a sizeable investment was unnecessary. After all, HIV/AIDS in California is being relatively well managed by combinations of antiretroviral drugs.

Sheehy argued, however, that these drugs are problematic and that he and many of his friends would happily trade them for the hope offered by a stem cell therapy. He described for the board the significant side effects of these medications and recounted in personal terms the increased rates of heart disease, non–HIV-related cancers, and neurological deficits that accompany HIV/AIDS infection. When critics discourage funding for stem cell therapies because they do not think anyone with HIV will participate in a clinical trial of such experimental procedures, he is there to say, "I would."

Changing landscape

The stories of Jeff Sheehy's activism, public dialogues in Taiwan, and James Grifo's patient all suggest that the relationship between the scientific sphere and the public sphere is changing. No longer are scientists seen as appropriately self-regulating. CIRM's inclusion of 10 patient advocates on its governing board also signals a new way of funding and guiding science.

It is also becoming increasingly clear that context matters—cultural, geographic, economic contexts surely, but also the specific details of each case. The mainstream media framed the Grifo-Zhuang case as controversial science, but it left out the context in which a woman, desperate for a biologically related child, prompted and funded the research. Although this detail may well raise additional questions about the ethicality of such funding arrangements, the details nonetheless matter. Individual patients are shaping emerging research.

On the international stage, despite variations in how different countries approach bioethics, the guidelines for human embryonic stem cell research developed by the International Society for Stem Cell Research have found relative acceptance in almost all countries where such research is being conducted. Also, in 2011, nearly a decade after the Grifo-Zhuang controversy, Britain's esteemed Nuffield Council on Bioethics approved a new IVF technique that involves replacement of the mitochondrion rather than the entire nucleus of a patient's egg. Though this approach raises very similar ethical concerns, the media response to date has been fairly neutral.

Slowly changing mores are not comforting to someone hoping for a cure to a disease or a chance to bear a child. Nor are they comforting to people who see them as a slippery slope that threatens human integrity and flourishing. But increasingly, locally and globally, bioethical decisions are including more voices, of individual scientists and patients and activists alongside scientific leaders and formal ethicists. Science and bioethics are indeed global endeavors, and now new kinds of relationships and new voices are emerging within and across borders.

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This is the fourth in the New Voices, New Approaches series of articles that have emerge from the "To, To Write, To Publish" workshop at Arizona State University. Funded by the National Science Foundation and directed by Lee Gutkind, the program pairs young academic scientists with professional writers to produce articles that use narrative to communicate more effectively and more engagingly with a broad readership.