Conclusion

One week in late April 2016, my wife and I traveled to Paris to attend the European Union Workshop on Human Genome Editing. Ellen was a member of the international committee commissioned to come up with guidelines for regulating research and therapy in this contentious area. I was along as an amateur ethnographer, observing the rituals of this highly educated, ideologically diverse tribe called the "policy community."

Over the years, I had been to enough such meetings to know some of the principal players by name. There was the cochair, Alta Charo, a plain-spoken, fiercely intelligent law professor from the University of Wisconsin. Born in Brooklyn, with a bachelor of arts degree in biology from Harvard and a juris doctor degree from Columbia, she has served on numerous bioethics committees over the years and became a member of the National Academy of Medicine in 2006. She loves old movies, Jane Austen, and science fiction, and is about as amiable a companion as you can have for an afternoon exploring the little side streets of l'Hôtel-de-Ville. Sharon Terry was there, the president of the Genetic Alliance, one of the most successful patient advocacy groups in the world. A former nun with a master of arts degree in religious studies, she became interested in genetics when both her children were diagnosed with pseudoxanthoma elasticum (PXE), an autosomal recessive disease of the connective tissue that can cause vision loss, narrowing of the arteries, pain during exercise, and other symptoms. Jeffrey Kahn, one of the current leaders in bioethics, was a speaker. He is a handsome man who looks a bit like he came from a lost branch of the Kennedy family. His doctorate is in philosophy, and he has an unusual ability to argue clearly about complex matters in a considerate, thoughtful tone.

The meetings were held in the august chambers of the Académie Nationale de Médecine on Rue Bonaparte, and in honor of the gathering, its library had assembled an exhibit of letters about medical education received by members of the French Academy from Benjamin Franklin and John Adams. The proceedings followed the same format as countless

literature conferences I have attended over the years. Only the panels were titled things like "Potential Applications for Germline Editing," "International Governance Perspectives," and "Regulatory Orientations." Some readers of this book might quail at the thought of spending several days in an auditorium listening to talks on such topics, but in fact, the presentations touched on issues of concern for every citizen, and like most policy talks, they were easy to understand.

Just as interesting as the speakers were the participants in the audience. As I circulated during the breaks, I met representatives from Doctors without Borders, the Defense Advanced Research Projects Agency (DARPA), the World Health Organization, the Wellcome Trust, the LeJeune Foundation (a Down syndrome and antiabortion advocacy group), the Chinese Academy of Science, and the Vatican. I talked with scientists who specialized in genetics, cancer biology, nanotechnology, artificial intelligence, physical chemistry, and pharmacology. I met a sociologist, a futurologist, and a professor of science communication. We heard from the entrepreneur who founded Bento Bio, which makes home laboratories that let you "experience genetics anywhere." The representative from the Vatican made clear his opposition to meddling with the human genome, but I could not get much out of the well-dressed, young woman from DARPA – "Genetically modified super soldiers?" I hinted, striving to make my Southern accent so artless that butter would not melt in my mouth. But she just smiled and said "DARPA sends me to all kinds of interesting events."

The committee was convened in response to the advances that CRISPR/Cas9 has made possible in changing the human genome. For the first time, scientists can now edit sequences of DNA with relative safety and precision, making possible the kind of direct intervention in the genome that people expected to follow hard on the heels of sequencing the human genome back in the early 2000s. Those were heady days. President Clinton compared Francis Collins and Craig Venter, the leaders of the two teams that had raced to complete the map of the human genome, to Lewis and Clark and Galileo, and he proclaimed, "Today, we are learning the language in which God created life." People were predicting fabulous new cures for existing diseases in short order. President Clinton joined the chorus: "it is now conceivable that our children's children will know the term 'cancer' only as a constellation of stars" (Clinton). At the same time, there were dire predictions of designer babies made to order over the internet; of a super-intelligent elite ruling over the unenhanced masses; and of terrible mutations sweeping through the species like a pandemic.

After a few years, however, scientists came to realize that progress was not going to be quick or easy. The existing methods of delivering genome therapies were not accurate enough to reach targeted regions of DNA consistently, and the risk of unintended changes in other parts of the genome was far too high for human interventions to be permissible. As more than a decade passed without the astounding advances promised by some of the architects of the Human Genome Project, disillusionment set in. But CRISPR/Cas9 changed all that. Once again, we are in a time of high promise and imminent peril.

An international committee like the one meeting in Paris was imperative, because attitudes toward editing the genome vary widely across the globe. When it comes to heritable modifications, the UK regulation is more flexible than that of the United States, France, or Germany. Some countries in Latin America are vigorously opposed to *any* heritable intervention in the genome. China, on the other hand, was the first to engage in CRISPR/Cas9 research that could be used to alter the genetic makeup of humans, and a renegade Chinese scientist subsequently announced the birth of gene-edited twins.

After the Paris meeting, the international committee held another public hearing in Washington, DC, and then went into intensive private sessions in which they hammered out a set of "Global Principles for Research and Clinical Use" and developed recommendations for regulatory approaches to basic laboratory research, somatic genome editing, germline editing, and enhancement. Like all National Academy reports, it is available for free at the Academy's website (*Human Gene Editing*).

The recommendations are sensible, in my view, and will be useful in clarifying the options for governments, medical professionals, disciplinary organizations, and funders around the world. The Global Principles were fairly anodyne, as any set of international ethical principles would have to be. Still, they were worth stating: "Promoting Well-Being, Transparency, Due Care, Responsible Science, Respect for Persons, Fairness, and Transnational Cooperation." There were some surprises in the report, however. The committee found that current regulatory structures were adequate for laboratory research and somatic genome editing, but they suggested some restrictions. Countries should "limit clinical trials or therapies to treatment and prevention of disease or disability at this time" (i.e., no enhancement); "evaluate safety in the context of risks and benefits"; and "require broad public input." For germline editing, the committee was more cautious, recommending that clinical research trials be permitted only for "compelling purposes of treating or preventing serious

disease or disabilities, and only if there is a stringent oversight system" (National Academies, *Human Genome Editing*).

What many people found surprising was that the committee had suggested letting human germline editing go forward at all. Some in the press treated this conclusion as astounding. The *New York Times* said the National Academies had for the first time "lent its support to a once-unthinkable proposition" (Harmon). The *Washington Post* characterized it more temperately: "the new report takes a slightly more permissive, forward-thinking position, saying that, if and when such interventions are proved safe – which could be in the near future – and if numerous criteria are met to ensure that such gene editing is regulated and limited, it could potentially be used to treat rare, serious diseases" (Achenbach).

It will be interesting to watch how the ethical debate and regulatory process proceeds over the next few years. The National Academies report does not carry the force of law, of course – none of the studies produced in the policy sphere does. But it will have great influence on future discussions.

On the last night of the Paris meeting, I was invited along with the other spouses for a dinner cruise on the Seine. As I dressed for the evening, I could not help feeling a bit amused. A dinner cruise for tourists? The night promised to be cold, and it was already raining. But I shouldn't have worried. After the intensity of the deliberations, everyone was ready to relax and set aside disagreements. When you counted up committee members, staff, and all their guests, we were more than forty in number, seated on both sides of a long table stretching nearly the full length of *Le Calife*, one of the familiar tourist boats that ply the Seine nightly. We set sail on choppy waters, but the buildings lit up on either bank slipped by in undiminished splendor. I was seated across from a sociologist of religion and a communications scholar from Germany and was flanked by two geneticists. They were delightful companions, full of entertaining stories to complement the good wines and somewhat rubbery *le blanc de poulet*.

When my dinner companions heard about the book I was writing, they wanted to know which was my favorite novel about genetics. It all depends on my mood, I replied. Some are beautiful, others melancholy, some fierce, some complex, and some simply thrilling. Later came a more pressing question: Why do novels matter? It was the geneticist to my left asking, and perhaps he really meant, why should he care what a novelist had to say about science. I was not going to rise to the bait, but I could not help reflecting on the components that were going into the consensus statement they were working so hard to prepare. Each committee member

on that boat spoke from a position of authority, but where did that authority come from? I looked down the long table and suddenly found myself imagining I was in one of those satiric dinners so common in novels by Thomas Love Peacock, where each character bore an allegorical name: Science, Religion, Law, Philosophy, Public Opinion, Commerce, Personal Experience. If deference were to be paid to Religion, why not to the "wise books, bright windows, in this life of ours," invoked by the narrator of *The Island of Doctor Moreau*? If Commerce, in the guise of a marketer of home genetics kits, can advise on the law governing gene editing, why not someone who has thought deeply about dystopian visions of the future? If Personal Experience of children with a genetic disease is to have her say, why not Margaret Atwood too? If Leon Kass and Francis Fukuyama can premise their arguments against tampering with the genome on simplistic readings of *Brave New World*, why not someone who understands Huxley in the context of both his own time and today? If we listen to Public Opinion, why not to the poetry that forestalled violence at the end of Ian McEwan's *Saturday*:

> Ah, love, let us be true
> To one another! for the world, which seems
> To lie before us like a land of dreams,
> So various, so beautiful, so new,
> Hath really neither joy, nor love, nor light,
> Nor certitude, nor peace, nor help for pain;
> And we are here as on a darkling plain
> Swept with confused alarms of struggle and flight,
> Where ignorant armies clash by night.
>
> Mathew Arnold, "Dover Beach"

Some believe that gene editing promises to save lives. Some believe that genetics will one day be able to predict our entire future. Some believe science will ultimately discover the Truth about the universe. Literature offers other forms of meaning. It gives access to different kinds of truth and has the power to heal the spirit if not the body. Art may not literally save our lives, but it might make us better understand why lives are worth saving. Yes, the promise of literature often seems more diffuse and metaphysical than that of science. But there is one pragmatic function of literature that this book has urged us to embrace, and that is the role that literature might play in dialogues about the values our societies hold dear at a time when the world needs such voices more than ever.

Our dinner cruise was nearing its destination, the Eiffel Tower. We had heard that each night at nine, the tower lit up in a grand display. The

dinner had been festive, but the room was growing hot and loud with the windows closed against the rain. While we waited for dessert, Ellen and I decided to walk outside where an awning at the front of the boat gave us partial shelter against the weather. The tower loomed above us in the night, impressive even in the dark. As we watched, the structure burst into light, strands of gold blazing from the base to the very top. It was a glorious sight, and it did away with any lingering weariness we were feeling from the din of the party. Then it was time to go back inside. There was dessert to be enjoyed and farewells to be said.