cular diseases, it created its own laboratory, Généthon, which published the first physical maps of the human genome and handed them over to the United Nations Educational, Scientific, and Cultural Organization (UNESCO) in 1993, as a heritage to humanity.

Numerous patient organizations concerned with rare diseases (80% of which are of genetic origin), national alliances, and a European umbrella organization (Eurordis—European Organization on Rare Diseases) have been created and have adopted and adapted this model of partnership with research and health institutions. The “Marche des Maladies Rares” (shown in the photo above) is an annual charity walk organized by the French Alliance on Rare Diseases. This collective mobilization is what led the European Union in 2009 to ask its member states to consider rare diseases a public health issue.

The fact that the complete genome sequences are now available has had effects on patient advocacy. First, from my observations in France, patient organizations have multiplied, notably because many genetic abnormalities (and not only genes) have been discovered. Second, thanks to knowledge derived from the sequencing of the complete genome, patient organizations are confronting the complexity of their diseases in their multiple, heterogeneous, and sometimes singular manifestations. As a consequence, the very definition and contours of the conditions they are concerned with sometimes become strategic elements in their self-descriptions. Third, because the same biological pathways might be involved in different conditions, patient organizations are considering cross-condition research subjects and issues.

What lessons can be learned from patient organizations’ active participation in genetic and now genomic research? First and foremost, it has shown lay people’s ability to engage in activities that were considered for a long time as the preserve of specialists. Second, patient organizations have made a crucial contribution to the socialization of genetic diseases. Through their involvement in research, they have fostered a strong sense of solidarity with patients whose diseases were, until recently, considered to be shameful defects that excluded them from a common humanity.

The Genome Dances

Liz Lerman
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As the work to map the human genome was finishing, I began to contemplate a performance piece exploring some of the meanings inherent in genetic discovery. As often happens, my research endeavors yielded too much data, and I soon recognized that a dance about the human genome could be a dance about religion, capitalism, policy, race, population control, or a dozen other topics. But after exploring the subject for a year through encounters with scientists, I settled on a format that framed the surprising commonalities of art and science and ventured to use the medium of dance as a science delivery system, setting up three topics: aging, ancestry, and perfection. The dance eventually premiered in 2006 as Ferocious Beauty: Genome, a work combining live dance with video projections that capture the faces, voices, and moving bodies of some of our wonderful science collaborators.

So for me, having the genome in hand meant that scientists were ready to talk to an artist—an essential element in my ability to create this work. Amid sensationalistic speculations and Frankenstein scenarios, the geneticists, biologists, and ethicists I engaged seemed eager for a platform that would bring a personal voice, a sense of beauty and history, and a range of feeling to bear on this most human of topics. Audiences throughout North America have responded in kind: “I didn’t expect it to be so emotional.” “I didn’t realize how human scientists were.” “I expected to be confirmed in my hatred for science, but now I have to reconsider.” Along this path, I encountered amazing scientists pursuing knowledge with passion, creativity, and leaps of imagination that were akin to those of my own art-making colleagues. I found a commitment to embracing wide paradoxes, such as how we humans are both common and unique. I discovered both a profound interest in personal inquiry in the lab and a commitment to preparing the larger public to handle the outcome of all this research. After 5 years of taking this dance to communities throughout North America, I have made many new friends in a field that is not so far from my own, although we have been trained to think we are separate.
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