



ANNAS

**Worst Case Bioethics**

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Death, Disaster, and Public Health

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## Genetic Genocide

Genetics tends to be discussed in extremes, in best case and worst case scenarios, and so provides a fitting subject for the final chapter. It brings us back to the first chapter on healthcare reform because of a best case scenario in which genomic or personalized medicine is seen as the future of US healthcare. I also use genetics to summarize my own worst case bioethics scenario: the creation of better humans, which would bring with it the prospect of what I have termed “genetic genocide,” and to consider whether this worst case scenario has been more distracting than illuminating in what has been termed the “genetically enhanced human” or germline genetic alteration debate.

Genetics is often viewed as a potential medical savior not just through personalized medicine in the developed world,<sup>1</sup> but also by applying genetic technology in the resource poor world.<sup>2</sup> There is an extensive literature on the bioethical issues involving genomics in both Europe and the United States. Bioethics has been used to frame the relationship between *Genomics and World Health* by the World Health Organization as well. Although, as previously noted, the WHO has adopted a health and human rights perspective, in their 241-page report on genomics and world health, human rights are mentioned only once, and then in the context of genetic

enhancements; that is, using genetic manipulations to try to make better babies or simply better humans:

Societies have a moral obligation grounded in equity or justice and human rights to ensure access to health care for their citizens. A fundamental part of *the moral imperative of health care is its role in maintaining normal function*, and in turn helping to secure equality of opportunity for persons that serious disease and disability undermine. *Genetic enhancements of normal function, on the other hand, do not serve justice* in this way and if and when they become possible, will almost certainly not be regarded as part of the social obligation to provide health care to all members of society.<sup>3</sup> (emphasis supplied)

Put another way, the Commission concluded that it is ethically acceptable that only some members of society, the elites, have access to the new genetics, and physicians who care for this elite can do so without worrying about bioethics. Whether one finds appeals to the norm of humanity or normal species functioning persuasive as a bright line that circumscribes the right to health or not, genetic technologies will change the way we think about ourselves and our species, and thus how we think about the rights of humans, including rights to health and healthcare, and even how we think about bioethics.

The overall question I address in this chapter is: Why do genetics and bioethics seem to be naturally paired in the context of both national healthcare and global health, and why, nonetheless, could a human rights framework—one focusing more directly on equality and the right to health itself—prove more useful than either a bioethics or a social justice frame in attaining global health?

As has been discussed in other contexts in this book, bioethics has dealt primarily with decisions made in the doctor–patient relationship (and secondarily with the researcher–subject relationship), whereas human rights doctrine has been more prominent, as reviewed especially in Chapter 13, in the global health arena. It is also in this latter context that bioethics and genomics have been most widely discussed. The risks of genomic research, for example, are highlighted in the WHO report. The report identifies three areas that present special risks: germline genetic alterations, the establishment of genetic databases, and the application of genomics to biowarfare.

The WHO authors conclude that it is premature and dangerous to attempt germline genetic alterations, that nothing can stop the establishment of population-based gene banks (but that rules to protect privacy and

guard against discrimination are required), and that the scientific community should take the risk of biowarfare applications of the new genomics seriously. The report concludes on mixed notes of hope and caution: The "new and rapidly evolving" field of genomics "offers considerable possibilities for the improvement of human health" but "the full extent of its possible hazards are not yet fully appreciated."

A Canadian group followed up the WHO report with an exercise designed to identify the new biotechnologies most likely to be helpful to improving the health of people living in developing countries. Their report, based on expert assessment using a Delphi methodology, put two genomic technologies at the top of their final list, and a related technology third: First, modified molecular technologies for affordable, simple diagnosis for infectious diseases; second, recombinant technologies to develop vaccines against infectious diseases; and third, technologies for more efficient drug and vaccine delivery systems.

The thesis of the Canadian report is that "biotechnology can help to bridge rather than deepen existing divides between the developed and developing world."<sup>4</sup> On the other hand, the authors recognize that there is no technological fix for health, and that we will require a balanced approach, "Biotechnology will never be a panacea to current health inequities, but the evidence demonstrates that it is rightly considered part of the solution." WHO's Commission arrived at a similar conclusion, emphasizing the central role of primary care in delivering any advanced medical technology: "None of these advances will be of any value unless the developing countries can evolve the healthcare systems on which these new advances can be based."

All this is pretty vague. It is uncontroversial to hope that the new genetics will help bridge the gap between the rich and the poor, and the developed world and the resource poor world, as it improves the lives and health of those it touches directly. But none of this will be automatic, and the WHO Commission was right to acknowledge the dark side of genetics to both health and development. I think the Commission could have gone much further in this regard, and would have had the Commission employed a human rights framework instead of the more limited bioethics-social justice framework in their analysis. Here's how, I think, it should be examined in the contexts of equality and the right to health.

### Equality and Genomics

Equality based on human dignity (sometimes denoted simply as the principle of nondiscrimination) is at the core of a health and human

rights approach to health. For example, a country's obligation to respect and protect the right to health requires governments to "refrain from denying or limiting equal access to all persons" and to ensure "equal access to healthcare...." The new genetics can be seen as scientific validation of human equality in that it demonstrates that we all share substantially identical genomes; but it can also be used to foster prejudice and discrimination and thus to undercut the right to health. The human tendency is to create divisions, which I'm sure at least some people would describe as genetic. This tendency is well-illustrated by James Watson, the co-discoverer of the structure of DNA, who scandalously told a British newspaper, "I'm inherently gloomy about the prospect of Africa because all our social policies are based on the fact that their intelligence is the same as ours, whereas all the testing says not really." Watson later apologized and acknowledged that no scientific evidence supports his statement about innate or genetic differences of intelligence among races. *Nature* magazine editorialized that Watson's remarks were "rightly...deemed beyond the pale," but also warned: "There will be important debates in the future as we gain a fuller understanding of the influence of genetics on human attributes and behavior. Crass comments by Nobel laureates undermine our very ability to debate such issues, and thus damage science itself."<sup>5</sup>

Our superficial perceptions of each other often foster racism. Simply defined, racism is "the theory that distinctive human characteristics and abilities are determined by race." The hunt for genes, especially in groups labeled by racial classifications, could lead to "genism" (a term I define as "the theory that distinctive human characteristics and abilities are determined by genes") based on DNA sequence characteristics. The resulting discrimination could be as pernicious as racism. In this context, Watson's ignorant remark can be seen not as one of an old-time racist, but the remark of a new-style "genist."

The great human rights hope of genetics has been that it will scientifically demonstrate that humans are all essentially the same, and that this demonstration will inhibit our penchant for drawing arbitrary distinctions among humans. And genetics has already accomplished much of the science part. After the draft of the human genome was announced in 2000, for example, Chris Stinger of London's Natural History Museum observed, "We are all Africans under the skin." The same point was made by other geneticists in different words, one noting that "race is only skin deep" and another, that "there is nothing scientific about race: no genes of any sort pattern along racial lines." Craig Venter, the leader of the private genome mapping effort, concluded: "Race is a

social concept, not a scientific one. We all evolved in the last 100,000 years from the same small number of tribes that migrated out of Africa and colonized the world.”

Geneticists deserve high praise for getting this antiracism message out to the public early. Unfortunately, the message of genetics, while undercutting racism, can simultaneously make old-fashioned racism seem scientifically-based by invigorating its evil brother, genism. This is how it works. As geneticists have observed, although we humans are all more than 99.5% genetically identical, that less than .5% of difference is made up of 15 million spelling variations in our genomes. Each of these genetic variations could be used as a pseudoscientific basis for discrimination based on genetic endowment.

Genome leaders have recognized this, and this recognition is one reason they helped to successfully lobby for enactment of the Genetic Information Nondiscrimination Act of 2008, which seeks to prohibit genetic discrimination by employers and health insurers.<sup>6</sup> This is reasonable, but as suggested in the preceding chapter on bioidentifiers, antidiscrimination legislation itself provides no effective genetic privacy protection. This is because genetic discrimination can only occur if private genetic information is shared—and to protect genetic privacy, we must not only ban the result of sharing information, genetic discrimination, but also regulate the collection, analysis, and storage of DNA samples and genetic information in the first place.<sup>7</sup> There is some irony in the fact that James Watson’s genome is one of the few that has been sequenced. After his offensive remarks, an analysis of Watson’s own genome was published. Watson’s genome disclosed that he has, according to Kari Stefansson of deCODE Genetics, 16 times the number of genes considered to be of African origin than the average white European, or about the same amount of African DNA that would show up if one great-grandparent were African.<sup>8</sup> This does not, except perhaps to a genist, mean that Watson is African—but it does help demonstrate that genes alone tell us very little about the social construct we call race, and little about full-bodied humans—even about genetic predisposition to disease, which remains largely an area dominated by a handful of predictive genes for rare diseases. In the arena of common diseases, such as diabetes and heart disease, in which multiple genes—as well as multiple environmental factors—are involved, most scientists believe we have yet to discover any genetic variants of clinical significance.<sup>9</sup>

The WHO Commission was also right to worry about the proliferation of DNA banks and the lack of agreement on how to protect the genetic privacy of those whose DNA is stored and analyzed in these DNA banks. In addition to biosecurity and police DNA databanks, discussed in the

preceeding chapter, an especially disturbing example of a human rights violation spurred by genetics is provided by the now defunct Human Genome Diversity Project, which sought to collect DNA samples from some 700 isolated ethnic groups, sometimes referred to as the world's "vanishing tribes." In the project's view, it was more important that science seize the opportunity to collect DNA from these peoples than that action be taken to help the peoples themselves. The indigenous peoples around the world properly and forcefully rejected this project, and insisted that their human rights be placed above this dubious and reductionistic DNA collection project.<sup>10</sup> A variation of this project has reemerged in another guise under the rubric of the Genographic Project which is sponsored by *National Geographic*.<sup>11</sup>

It is true that "we are all Africans under the skin." It is also true, however, that if we decide to search for genetic differences in the .5% of our DNA that is different, we will find them and likely wind up using them against each other. Philosopher-bioethicist Eric Juengst put it well: "No matter how great the potential of population genomics to show our interconnections, if it begins by describing our differences it will inevitably produce scientific wedges to hammer into the social cracks that already divide us."<sup>12</sup>

Preventing genism from displacing or supplementing racism by substituting molecular differences for skin color differences will not be easy. Two actions, however, seem necessary. First, genetic privacy must be protected. No one's genes should be analyzed without express authorization, and, of course, no "genetic identity cards" should be permitted. In this regard, the decision of the European Court of Human Rights, discussed in the preceeding chapter, is directly on point in ruling against human rights violations of governments holding genetic samples from individuals who have not been convicted of crimes. Second, pseudoscientific projects that purport to identify genetic differences between races should be rejected.<sup>13</sup>

### Genetic Genocide

The WHO Commission may seem to have spent too much time and emphasis on describing the use of genetics to enhance human beings by making changes at the embryo level that could produce better babies. But I don't think so. Even though altering the genome of an embryo to create specific characteristics in the resulting child is not currently possible, it is a subject that deserves far wider attention, especially in the human rights



community. James Watson, this time from statements he made at a 1998 conference on *Engineering the Human Germline*, again provides a useful introduction:

It seems to me the question we are going to have to face is, what is going to be the least unpleasant? Using abortion to get rid of nasty genes from families? Or developing germline procedures with which . . . you can go in and get rid of a bad gene . . . And the other thing, because no one has the guts to say it, *if we could make better human beings by knowing how to add genes, why shouldn't we do it?* What would be wrong with it? . . . *If you could cure what I feel is a very serious disease—stupidity—it would be a great thing* for people who are otherwise going to be born seriously disadvantaged.<sup>14</sup> (emphasis supplied)

Watson's comment on curing stupidity through genetics led him to accept an invitation from Steven Colbert to say more on Jon Stewart's *Daily Show*. Colbert showed Watson all the respect he deserved for his suggestion in the filmed interview, in which Watson said, among other things, "If you want smart children, don't marry a bimbo." Screening genomes to detect differences creates more opportunities for discrimination. Using the new genetics to try to make a better human by genetic engineering, I have previously suggested, goes beyond discrimination and genism to elimination, raising the prospect of genetic genocide. I have also suggested that both cloning and inheritable genetic alterations "can be seen as crimes against humanity of a unique sort: techniques that can alter the essence of humanity itself by taking human evolution into our own hands and directing it toward the development of a new species, sometimes termed the posthuman."

Is this inflammatory, apocalyptic, worst case scenario language justified? I think it is, but only as a counterpoint to what I take to be the implausible best case utopian scenarios of Watson and his followers, who sell genetic manipulation as the cure for all our human problems. The project to make a better baby by genetic engineering begins with attempts to cure or prevent genetic diseases, but inevitably leads to the eugenic agenda of improving or "enhancing" genetic characteristics to create the super-human or posthuman.

Posthuman proponents Lee Silver and John Harris, for example, have used as their central vision genetic manipulation of a human embryo that will create a child who is immune from HIV or cancer, and ask, who could object to this? They are correct that few, if any, would object to the prevention of a serious disease, including HIV and cancer. Nonetheless,

we might wonder whether performing a genetic experiment on an embryo that could have unknown deleterious consequences to the soon-to-be child, or consequences we might not see for generations, is ethically justifiable. We might also wonder who, if anyone, has the moral authority to consent to this extreme human experiment. Our questioning seems especially appropriate when the same result might be obtained with a safe alternative, such as vaccination—as it has been in the cases of smallpox and polio—without requiring every future child born to have undergone a genetic modification at the embryo stage to attempt to prevent or eradicate a serious disease.

But even if we think embryo modification to confer immunity to particular diseases should be a choice for prospective parents to make, it seems unlikely that the project would end there. Instead, the next phase would be to attempt to make not just a disease-resistant baby, but a “better baby” by attempting to improve traits like eye color, hair color, height, or even intelligence, strength, and beauty. This type of genetic manipulation of the embryo, if successful in creating a large number of significantly better babies (a large scientific “if”) creates with it the future prospect of genetic genocide as a reasonably possible, if not likely, conclusion. This is because, given the history of humankind, it is extremely unlikely that we will see the better babies or posthumans as equal in rights and dignity to us, or that they will see us, the “naturals,” as their equals. Instead, it seems reasonable to conclude that we will see them as a threat to us, and seek to imprison or simply kill them before they kill us. Alternatively, the posthumans could come to see us naturals as an inferior subspecies without human rights, to be enslaved or slaughtered preemptively, much as Europeans once viewed “uncivilized” peoples, the way we Americans viewed the Japanese in World War II, or the way the Germans viewed the Jews.

My pessimistic view is shared by many, if not most, of those who welcome a posthuman future. In a survey of members of the World Transhumanist Association, released in 2008, for example, only a minority (46%) agreed with the statement that “humans and posthumans will be able to coexist in one society and polity.” The transhumanists might see simple geographic separation as a solution. And we might get lucky. John Stuart Mill had great faith in our ability to use freedom to foster progress. But as Gertrude Himmelfarb has noted, Mill “looked to liberty as a means of achieving the highest reaches of the human spirit; he did not take seriously enough the possibility that men would also be free to explore the depths of depravity.”<sup>15</sup> But we must.

It is the potential for genocide based on genetic difference that makes species-altering genetic engineering a potential weapon of mass destruction, and makes the unaccountable genetic engineer a potential bioterrorist.

Is this assertion an overblown worst case scenario that could lead us to forfeit the potentially life-saving benefits of genetic manipulation? British bioethicist John Harris certainly thinks so, and has characterized the end of my first sentence in this paragraph as “rather strained huffing and puffing” based on “mere speculation about future possible effects” that “would deny millions of people and eventually the entire population of the planet access to possible life-saving and life-enhancing therapies.”<sup>16</sup> Harris also argues that I am wrong to suggest that the problem lies with the unaccountable genetic engineer. Rather, he believes, the problem lies with the parents (who are “all unaccountable”), and that blaming parents for their super-enhanced progeny is the equivalent of blaming Jewish parents for being the instigators of the Holocaust.

This is, I think, a silly—but nonetheless telling—argument. It is silly because it substitutes parents (who engineer nothing) for “unaccountable genetic engineers.” This is a serious category error: holding Mengele accountable for his lethal genetic experiments on twins in the Nazi concentration camps is not to blame his victims (or their parents—almost all of whom were murdered in the concentration camps) in any way. The genetic engineer (Nazi doctor) does bear responsibility for his crimes; the parents (Holocaust victims and their children) are blameless. Of course, if unlike the Jews in the concentration camps, contemporary parents consent to and encourage genetic engineering experiments on their future children, they would be complicit in this project, and also responsible for them. It is telling that by choosing the Nazi concentration camps for his example, Harris highlights the racial hygiene agenda of National Socialism, and its goal of creating a super race of superior Nordic stock that would treat all other humans as inferior, proper objects of German subjugation and even extermination. The ultimate goal was to carry out this project by eugenics. Thus, it appears that even Harris recognizes that genetic enhancement researchers, at least those in the category of the unaccountable experimenters, can produce an unacceptable risk of genocide.

The Nazi doctors were tried for murder and torture at Nuremberg, rather than genocide. But this was a historical anomaly, as the crime of genocide had not yet been accepted by the international community as a war crime or crime against humanity. Nonetheless, in their state sponsorship, their concentration camp murders did qualify as war crimes and crimes against humanity. Also, as discussed in Chapter 13, the Nuremberg Doctors’ Trial and the resulting Nuremberg Code set international human rights norms of human experimentation that apply globally.

Harris is, however, correct in arguing that if the real problem is racism and genism, or, as he puts it, “mindless prejudice,” the solution should be

to eliminate the prejudice, not eliminate the genetic engineering project. Here we agree on the goal, but not the efficacy of genetic engineering in achieving it. I doubt even Harris believes that there is a gene for prejudice, the way Watson has suggested that there is a gene for stupidity. To the extent that our view of human rights—including the principle of nondiscrimination—is based on our view of human nature, including human dignity, the human rights problem is that changing the characteristics of what it is to be human (and thus a member of the human species) could undermine both the concept of inherent human rights generally and the principle of nondiscrimination specifically.

What really seems to be in dispute then, as it is in virtually all the worst case scenarios explored in this book, is the probability of the worst case scenario actually occurring, and how high that probability must be to justify actions today to try to avoid it. Here we both engage in speculation. The issue is whether this is speculation informed by past experiences, or simply speculative fiction as cautionary tale. My own view is that given the frequency of human genocides in the past century, the probability of a future genocide based on genetically engineered differences (again, assuming germline genetic alterations become possible and predictable) is closer to 50% than Dick Cheney's 1%. This is why I have proposed application of the precautionary principle to germline genetic alteration experiments, which would shift the burden of proof to those who want to try to alter humans, rather than placing it, as it is now, on those who oppose it.<sup>17</sup>

A treaty outlawing replication cloning and germline genetic engineering does this directly by making the proponents of these technologies repeal the treaty before proceeding. This strikes many as an over-reaction, but shifting the burden of proof to corporations and scientists in this case is similar to what we currently do with new drugs and devices through the FDA. As discussed in Chapter 7, before a company is permitted to market a drug or device in the United States, it has the burden to demonstrate to the FDA, through scientific studies, that its product is "safe and effective." As argued in that chapter, with the exception of anti-government-regulation libertarians who worry about access to experimental cancer drugs, few people seriously contest this Hippocratic allocation of the burden of proof.

Overly optimistic commentators believe that simply failing to distribute the fruits of human genetics equitably could itself lead to the same "two species" result. James Evans, for example, has suggested that depriving the poor of personalized genomic medicine "runs the risk of creating a genetically defined underclass which, because of inheriting more than a fair share of disease-susceptibility genes, is unable to afford adequate [medical] care." Others think that the prospect of humans ever being able to engineer

a genetic elite is remote because of the difficulty of identifying genes for intelligence, for example, and using those genes to make more than minimal changes in offspring. As biologist Christopher Wills put it, arguing that environmental factors will continue to overwhelm genetics in the foreseeable future: "*The Boys from Brazil* notwithstanding, it seems likely that if clones of Adolf Hitler were to be adopted into well-adjusted families in healthy societies they would grow up to be nice, well-adjusted young men."<sup>18</sup> Maybe Wills is right. But is the entire world obligated to take this chance because one genetic scientist decides to do the experiment?

### What Future for Our Species?

Bioethics has been called on to help us regulate the research, distribute the benefits, and save us from the potential harms of the new genetics. With its focus on individual decisions made in the context of the doctor-patient relationship (and the researcher-subject relationship), however, it cannot, at least by itself, confront either global or species-wide issues. UNESCO's Universal Declaration on Bioethics and Human Rights is a step in the right direction of integrating human rights and bioethics. This attempted synthesis nonetheless suggests, as I argued in Chapter 13, that the language and practice of international human rights provides the most powerful approach to global governance of the new genetics.

In 2001, I suggested, with my colleagues Lori Andrews and Rosario Isasi, that the threat by cults and others operating on the margins of human society to clone a human being created an opportunity for the world to act preventively in ways that have been characterized as either extremely difficult or impossible. We believed that UNESCO's Universal Declaration on the Human Genome and Human Rights and the overwhelming repulsion of peoples and governments around the world to plans to clone humans made it reasonable and responsible to propose a formal treaty on The Preservation of the Human Species<sup>19</sup> (see box at p. 262). This proposed treaty would ban human replication cloning and germline genetic alterations. It is important to underline that adoption of this treaty would not mean that these techniques could never be legally used. What it would mean is that no individual, corporation, or government could lawfully experiment with these techniques without a worldwide discussion, followed by modification of the treaty to permit such experimentation.

To the extent that treaty negotiators and neutral scientists conclude that the prospect of genetic genocide is overblown, the treaty could be time-limited and expire automatically after the human species has gone for a

period of time, perhaps 50 years, without a genocide. Because few people who have criticized the proposed treaty seem to have read it, it is also worth emphasizing that nothing in the treaty is concerned with "preserving the human genome" in its current form. Rather its authors see no compelling reasons to either eliminate the need for sexual reproduction through cloning, or to attempt to take evolution into our own genetic engineering hands. The rationale for the prohibition is that those who make such attempts are potentially putting all humans at a worst case risk of extermination and therefore should reasonably have the burden of proving to a representative international body that the benefits of their experiments are more likely to be beneficial to the human species than lethal.

### **Convention on the Preservation of the Human Species**

Article 1: Parties shall take all reasonable action, including the adoption of criminal laws, to prohibit anyone from initiating or attempting to initiate a human pregnancy or other form of gestation using embryos or reproductive cells which have undergone intentional inheritable genetic modifications.

Article 2: Parties shall take all reasonable action, including the adoption of criminal laws, to prohibit anyone from utilizing somatic cell nuclear transfer or any other cloning technique for the purpose of initiating or attempting to initiate a human pregnancy or other form of gestation.

Article 3: Parties shall implement a system of national oversight through legislation, executive order, decree, or other mechanism to regulate facilities engaged in assisted human reproduction or otherwise using human gametes or embryos for experimentation or clinical purposes to ensure that such facilities meet informed consent, safety, and ethical standards.

Article 4: A Conference of the Parties and a Secretariat shall be established to oversee implementation of the Convention.

Article 5: Reservations to this Convention are not permitted.

Article 6: For the purpose of this Convention, the term "somatic cell nuclear transfer" shall mean transferring the nucleus of a human somatic cell into an ovum or oocyte. "Somatic cell" shall mean any cell of a human embryo, fetus, child, or adult other than a reproductive cell. "Embryo" shall include a fertilized egg, zygote (including a blastomere and a blastocyst), and a preembryo. "Reproductive cell" shall mean a human gamete and its precursors.

Our treaty proposal has not been acted on, and a similar treaty proposed by France and Germany was ultimately redrafted and adopted by the General Assembly of the United Nations as a declaration with no binding force. Unlike our proposal, the Declaration calls on countries to outlaw not just cloning to make a baby, but also cloning to produce stem cells to make medicine. Three events that occurred in 2009 may make it reasonable to reconsider our proposed treaty. The first is the inauguration of President Barack Obama and his rejection of the Bush administration's ban on stem cell research, at least research using surplus or "left over" IVF embryos. The United States would no longer insist, as it did during the Bush administration, that a treaty that bans human cloning and germline genetic engineering also bans the use of human embryos in research.

The second event is the first successful germline modification of a primate, a New World marmoset.<sup>20</sup> Japanese investigators reported that they had inserted a foreign gene into the marmoset embryo, and had thereby produced marmosets that incorporated the foreign gene (the gene coded for green fluorescent protein, GFP, into at least some of their tissues).<sup>21</sup> This had been done before (see Chapter 2 on the bunny named Alba and the monkey named ANDi). What was novel is that sperm was taken from one of the transgenic marmosets and used to create an embryo. The embryo was gestated by a "surrogate mother" who gave birth to a transgenic marmoset—the first time a transgenically altered primate had been able to have an offspring that also exhibited the added gene. This marmoset could have an impact on the discussion of possible human application of this technique second only to that of Dolly, the cloned sheep. Science commentators in the same issue of *Nature* in which the experiment was announced, have already warned that application of this technique to human gametes and embryos for reproductive purposes would be "unwarranted and unwise." They also wrote that the risks inherent in the technique demonstrated "the very real need for existing guidelines framed by professional societies and regulatory authorities which prevent germline genetic modifications in humans."<sup>22</sup>

The scientists are correct, but as demonstrated by the irresponsible actions of a few to try to make human babies by cloning, professional and regulatory action alone will not prevent attempts to modify the human germline.<sup>23</sup> This is apparent from the third example, the transfer of the nuclear genetic material from an egg with mutant or defective mitochondrial DNA to an egg with healthy mitochondrial DNA, and the subsequent birth of healthy rhesus macaque monkeys.<sup>24</sup> This germline genetic engineering technique, which results in a monkey with three genetic parents (with genes from the sperm, nucleus of one egg, and mitochondrial DNA

from another egg), was suggested for almost immediate research application in humans both by the monkey researchers and scientific commentators. *Nature* editorialized, for example, that using this technique at least "has the potential to give more couples the chance of having a healthy baby" and that "blanket bans can impede progress and encourage unethical practices."<sup>25</sup>

Is it too much to suggest that the births of the transgenic marmoset and the rhesus monkeys with three genetic parents provide the world with another opportunity to consider outlawing human germline genetic alterations by treaty?

Species-endangering experiments (including the creation of new genetically based bioweapons, as discussed in Chapter 2) directly concern all humans and should only be authorized by a body that is representative of everyone on the planet. These are arguably the most important decisions our species will ever make (although a reasonable case can be made that climate changes poses a more immediate survival problem for our species). And they are of special concern to the human rights community. It is not that the combination of birth, human DNA, and a human form are necessary conditions for human rights; but they are sufficient conditions for human rights. Nor is it that the human species can or should remain just the way it is (we can't), or that changes in humanity driven by evolution are not inevitable (they are). But these species changes are the result of adaptation to a new or changing environment, rather than the normative application of one particular view of human betterment or improvement. Moreover, to the extent that human rights law is grounded in our understanding of what it means to be human, changing the characteristics of the human species destabilizes that understanding and provides new tools that could encourage discrimination at best, and put the survival of the species itself at risk at worst. Cloning, for example, not only removes sexual reproduction from the definition of what it is to be human, but also seeks to eliminate human evolution by duplicating existing genomes. We have a tendency to simply let science take us wherever it will. But science has become so powerful, both in terms of making our lives better and raising the risk of worse case scenario species suicide, that we can no longer abdicate our protection responsibility to each other as members of the human species.

It is illusory to believe either that the new genetics is likely to do more good than harm to people in resource poor countries, or to believe that either bioethics or concepts of social justice alone provide sufficient guidance to deal with genetics research globally. We need a much wider, global framework and a more inclusive language—human rights—to both promote social justice and inhibit discrimination. We must work together to promote genetic privacy, prevent the genetic engineering of humans, and



promote and protect universal human rights based on dignity and equality. Without action on the species level there is at least a possibility of a worst case scenario species suicide.

This is, I think, about as much as can be said—and like all worst case scenarios, probability matters. If the probability of genetic genocide really can only be roughly quantified as “at least a possibility” then it is worth spending time, money and effort to deal with it only if no other more plausible “bad case scenarios” exist. Of course, there are many more plausible problems to work on in the reproductive genetics realm, including defining the limits of prenatal genetic screening, and deciding what pre-implantation embryo experiments, including mitochondria alterations, should be permissible and who should make this determination. I leave it to the reader to decide whether the prospect of genetic genocide is a distracting, science fiction scenario, or a plausible basis for motivating public policy; whether it has more in common with H.G. Wells and his *Time Machine*, Olaf Stapledon’s *Last and First Men*, or even Margaret Atwood’s *The Year of the Flood*, than with current scientific and medical developments in primate reproduction research.

At the conclusion of *Worst Case Bioethics* some broad conclusions seem reasonable. The first is that there are three basic rationales that governments (and private entities) consistently employ to justify almost anything they want to do: the action will save lives; promote national security and/or promote progress. These are powerful rationales (the fourth, reliance on free markets rather than government regulation lost much of its appeal during the global financial meltdown, but will likely make a comeback in the future), and are usually simply asserted without any factual or scientific basis. What they have in common is that they all embody an implicit worst case scenario: if we don’t do “X”, (hundreds, thousands, or millions of ) people will die, our country will be attacked (by terrorists or others), and/or we will remain ignorant (and reject all the good things more science and technology could bring the human race).

It has been frequently argued that “rights talk,” including the assertion of human rights, is a conversation stopper because rights are often used as trump cards to win arguments. This is, at best, an over statement. More commonly the three rationales, individually or together, act as conversation stoppers and sufficient justification for action. As best case scenarios they can usually only be countered by worst case scenarios – which can be either plausible or entirely fictional. There are three major counter-scenarios to those that promise to save lives, protect us and our country from harm, or simply help civilization progress: war crimes and crimes against humanity, including human experimentation without consent, risk to the planet, and

risk to the human species. When any of these are plausibly at stake, most people will listen to an argument for precautionary measures to limit risks, at least if it has a reasonable probability of occurring in the near future. Keynes after all was correct, "In the long run, we're all dead."

It is also worth underlining that all of our current concepts of human rights, including all of the major human rights documents, were developed and adopted in direct reaction to horrible human abuses of fellow humans—specifically those inflicted during World War II. It has been asserted that it is a paradox that recognition of human rights follows their gross abuse. It may be more accurate to say, however, that humans are able to understand and recognize human dignity only by witnessing it being violated. It takes the horrors of slavery, murder, torture, and genocide, to name just a few war crimes and crimes against humanity, for us humans to try to prevent these acts from being repeated. If this is so, then it is also reasonable to believe that compelling worst case scenarios, informed by historical precedent and scientific plausibility, could cause humans to take precautionary action before catastrophe strikes us. But maybe that's just too much to hope for.

Kurt Vonnegut, through one of his most compelling characters, science fiction writer Kilgore Trout, made this same point a different way. In *Breakfast of Champions* Vonnegut writes that as an "old, old man" Trout was asked by the Secretary General of the United Nations if he "feared the future." Trout responded, "Mr. Secretary-General, it is the *past* which scares the bejesus out of me."<sup>26</sup>

had the right to “invoke their own right and interest to personal privacy” and to “seek to be shielded by the exemption [7(c)] to secure their own refuge from a sensation-seeking culture for their own peace of mind and tranquility, not for the sake of the deceased.” In a sworn declaration, for example, Foster’s sister noted that she was “horrified and devastated” by a photograph that had already been leaked to the press: “I have nightmares and heart-pounding insomnia as I visualize how he must have spent his last few minutes and seconds of his life.” She added, “Releasing any photographs would constitute a painful unwarranted invasion of my privacy.”

As the Court construed it, the question was whether Congress had intended that the phrase “personal privacy” be read “to permit family members to assert their own privacy rights against public intrusions long deemed impermissible under the common law and in our cultural traditions.” The Court found in US “case law and traditions the right of family members to direct and control disposition of the body of the deceased and to limit attempts to exploit pictures of the deceased family member’s remains for public purposes,” and concluded that Congress intended to continue family privacy in this regard. The Court also found that the invasion of their privacy was “unwarranted” because no evidence of governmental impropriety was presented in regard to the investigation of Foster’s death. The Court therefore ruled that the Foster photographs could be kept from the public on the basis of family privacy. *National Archives and Records Administration v. Favish*, 541 U.S. 157 (2004).

27. Parker, M. and Lucassen, A.M., Genetic Information: A Joint Account? *British Medical Journal* 2004; 329: 165–67. See also Offit, K., Groeger, E., Turner, S., Wadsworth, E.A., and Weiser, M.A., The “Duty to Warn” A Patient’s Family Members About Hereditary Disease Risks, *JAMA* 2004; 292: 1469–73, and Annas, G.J., Reforming Informed Consent to Genetic Research, *JAMA* 2001; 286: 2326–28.

28. Editorial, An Afternoon at UK Biobank, *Lancet* 2009; 373: 1146.

29. Quoted by Rosen, *supra* note 14.

## Chapter 17, Genetic Genocide

1. This chapter is adapted from Annas, G.J., Bioethics and Genomics (in Andrew Clapham and Mary Robinson, eds., *Realizing the Right to Health*, Zurich: Ruffer & Rub, 2009, 321–9.

2. E.g., Maxwell J. Mehlman, *Wondergenes: Genetic Enhancement and the Future of Society*, Bloomington, Indiana: 2003.

3. Advisory Committee on Health Research, *Genomics and World Health: Report of the Advisory Committee on Health Research*, Geneva: World Health Organization, 2002.

4. University of Toronto Joint Center for Bioethics, *Top 10 Biotechnologies for Improving Health in Developing Countries*, Toronto: University of Toronto Press, 2005.

5. Editorial, Watson’s Folly, *Nature* 2007; 449: 948; Milmo, C., Fury at DNA Pioneer’s Theory: Africans Are Less Intelligent than Westerners, *The Independent*, October 17, 2007, 24. Watson has apologized many times for these remarks, but his apologies only serve to demonstrate his ability to talk without thinking. For example, on October 31, 2009, on the Charlie Rose Show, Rose asked him how “someone as smart as you [could] say what you did?” Watson replied, “Oh, I was saying something to a girl—I never thought of her as a reporter . . .”.

6. See, e.g., Baruch, S. and Hudson, K., Civilian and Military Genetics: Nondiscrimination Policy in a Post-GINA World, *American Journal of Human Genetics* 2008; 83: 435–44; and, Hudson, K., Holohan, M., and Collins, F., Keeping Pace with the Times: The Genetic Information Nondiscrimination Act of 2008, *New England Journal of Medicine* 2008; 358: 2661–63.

7. This is a proposal my colleagues Leonard Glantz and Winnie Roche and I made with the Genetic Privacy Act of 1995 discussed in George J. Annas, *Some Choice: Law, Medicine and the Market*, New York: Oxford University Press, 1998, 109–11.

8. Schwartz, J., DNA Pioneer's Genome Blurs Race Lines, *New York Times*, December 12, 2007, A24. In her disturbing and evocative novel of post apartheid South Africa, *The House Gun*, Nadine Gordimer writes of Harold and Claudia Lindgard (the parents of a young man who has killed his friend):

The Lindgards were not racist, if racist means having revulsion against skin of a different color, believing or wanting to believe that anyone who is not your own color or religion or nationality is intellectually and morally inferior. Claudia [a physician] surely had her proof that flesh, blood, and suffering are the same, under the skin. Harold surely had his proof in his faith that all humans are God's creatures in Christ's image, none above the other. Yet neither had joined movements, protested, marched in open display, spoken out in defense of these convictions. They thought of themselves as simply not that kind of person; as if it were a matter of immutable determination, such as one's blood group, and not failed courage.

Gordimer was the headliner on the 2001 UNESCO panel at UN Racism Conference in Durban at which the original version of this chapter was first presented. It took direct action to overcome apartheid. Although the Lindgards seemed to believe in behavioral genetic determinism, there is no gene (or blood characteristic) that codes for or excuses inaction in the face of actual or threatening human rights abuses.

9. See, e.g., Kraft, P. and Hunter, D., Genetic Risk Prediction: Are We There Yet?, *New England Journal of Medicine* 2009; 360: 1701–03. Public health can also be a handmaiden of the new genetic discrimination, rather than a force for social justice and human rights in this new regime. As epidemiologist Philip Alcabes has put:

We all agree that race doesn't exist biologically. There is no DNA signal that reproducibly encodes blackness or whiteness. But talk of risk makes it seem that it does. To identify African American "ethnicity" as a correlate of susceptibility to prostate cancer, as a recent report in *Nature Genetics* does, or to license a heart-failure medication for African Americans only, as the Food and Drug Administration has done, is to create a biological race where none exists. To claims, as a recent article in the *American Journal of Epidemiology* does, that race is associated with higher levels of "risk behaviors" (in this case, smoking cigarettes and marijuana, and drinking alcohol) is not only to misappropriate the idea of risk in order to condemn disapproved activities;

it also reifies race by associating it with presumptively noxious, morally reprobated behaviors. Alcabes, P.; What Ails Public Health?, *Chronicle of Higher Education*, Nov. 9, 2007, B6-8.

10. National Research Council, *Evaluating Human Genetic Diversity*, Washington, D.C.: National Academies Press, 1997.

11. For more on this project see <https://www3.nationalgeographic.com/genographic/> (accessed April 23, 2009).

12. Juengst, E., Groups as Gatekeepers to Genomic Research: Conceptually Confusing, Morally Hazardous, and Practically Useless, *Kennedy Institute of Ethics Journal* 1998; 8: 183–200.

13. See Commentary: Should Scientists Study Race and IQ?, *Nature* 2009; 457: 786–89. (Steven Rose argues “no” and Stephen Ceci and Wendy Williams argue “yes.”)

14. Quoted in Gregory Stock and John Campbell, eds., *Engineering the Human Germline: An Exploration of the Science and Ethics of Altering the Genes We Pass to Our Children*, New York: Oxford University Press, 2000, 79. Watson has also consistently argued against any sort of international agreement on genetic engineering: E.g., “I think it would be complete disaster to try and get an international agreement. I just can’t imagine anything more stifling. You end up with the lowest possible denominator. Agreement among all the different religious groups would be impossible. About all they’d agree upon is that they should allow us to breath air.... I think our hope is to stay away from regulations and laws whenever possible” (Id. at 87).

15. Quoted in Richard Reeves, *John Stuart Mill: Victorian Firebrand*, London: Atlantic Books, 2007, 284.

16. John Harris, *Enhancing Evolution: The Ethical Case for Making Better People*, Princeton: Princeton University Press, 2007, 23–25. Although one of the major problems with germline genetic engineering is the ethics of risky research on children (and would-be children), Harris dismisses this issue out of hand by arguing that parents should be able to make research decisions for their children, and that humans in general have a “duty” to be research subjects. The former argument is, I think, simply untenable, and the latter has been refuted by Brassington, I., John Harris’ Argument for a Duty to Research, *Bioethics* 2007; 21: 160–68. See also Ronald Bailey, Transhumanism and the Limits of Democracy, April 28, 2009 (available at [www.reason.com](http://www.reason.com)), who argues that our suggestion (previously published in note 17, *infra*) is an “over-the-top scenario” that should be taken “down a notch or two.” On the prospect for genetic genocide, Bailey argues that “It is an unfortunate historical fact that plenty of unenhanced humans have been quite capable of believing that millions of their fellow unenhanced humans were inferiors who need to be eradicated.” He agrees that future genocides are possible, but that the risk is greatly outweighed by the benefits, such that banning enhancement technologies would involve “huge social costs.”

17. Annas, G.J., Andrews, L., and Isasi, R., Protecting the Endangered Human: Toward an International Treaty Prohibiting Cloning and Inheritable Alterations, *American Journal of Law & Medicine*, 2002; 28: 151–78. Updated in

George J. Annas, *American Bioethics: Crossing Human Rights and Health Law Boundaries*, New York: Oxford University Press, 2005, 43–58.

18. Wills, C., Evolution Theory and the Future of Humanity (in) Nick Bostrom and Milan Cirkovic, eds., *Global Catastrophic Risks*, New York: Oxford University Press, 2008, 64. The quotation from Evans is from his Health Care in the Age of Genetic Medicine, *JAMA* 2007; 298: 2670–72.

19. Supra note 1, See also Annas, G.J., The ABCs of Global Governance of Embryonic Stem Cell Research: Arbitrage, Bioethics and Cloning, *New England Law Review* 2005; 39: 489–500; Isasi, R. and Annas, G.J., Arbitrage, Bioethics, and Cloning: The ABCs of Gestating a United Nations Cloning Convention, *Case Western Reserve Journal of International Law* 2003; 35:397-414; and International Bioethics Committee of UNESCO, *Report of the IBC on Human Cloning and International Governance*, June 9, 2009 (“IBC is of the position that, although it may be premature for the international community to engage now in the elaboration of a new binding normative instrument aimed at harmonizing both practices and principles in this area, the issues surrounding the international governance of human cloning cannot be ignored and a focused international dialogue is crucially needed.”). The proposed Convention would also prohibit the use of so-called synthetic biology techniques to create a genetically-modified child. See, e.g., Specter, M., A Life of its Own: Where will Synthetic Biology Lead Us?, *New Yorker*, September 28, 2009, 56–65.

20. Editorial, Time to Connect, *Nature* 2009; 459: 483, and Cyranoski, D., Marmoset Model Takes Center Stage, *Nature* 2009; 459: 492.

21. Sasaki, E. et al., Generation of Transgenic Non-human Primates with Germline Transmission, *Nature* 2009; 459: 523–27.

22. Schatten, G. and Mitalipov, S., Transgenic Primate Offspring, *Nature* 2009; 459: 515–16.

23. E.g., the Raelians. See Rael, *The True Face of God* (published by the Raelian Religion, 1998), and see also generally, Joel Garreau, *Radical Evolution: The Promise and Peril of Enhancing our Minds, Our Bodies—and What it Means to be Human*, New York: Doubleday, 2004, and Maxwell Mehlman, *The Price of Perfection: Individualism and Society in the Era of Biomedical Enhancement*, Baltimore: Johns Hopkins University Press, 2009.

24. Tachibana, M., Sparman, M., Sritanaudomchai, H. et al., Mitochondrial Gene Replacment in Primate Offspring and Embryonic Stem Cells, *Nature* 2009; 461: 367–76.

25. Editorial, The Ethics of Egg Manipulation, *Nature* 2009; 460: 1057, and see Shoubridge, E.A., Asexual Healing, *Nature* 2009; 461: 354–55.

26. Kurt Vonnegut, *Breakfast of Champions*, New York: Dell, 1973, 187. Margaret Atwood’s character, Adam One, describes our predicament poetically: “Then they [we] fell from a joyous life in the moment into the anxious contemplation of the vanished past and the distant future.” *The Year of the Flood*, New York: Doubleday, 2009, 188.