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MAPPING THE HUMAN GENOME AND THE MEANING OF MONSTER MYTHOLOGY†

George J. Annas*

Pre-Columbian cartographers drew their maps to the extent of their knowledge, and then wrote in the margins, "Beyond this point there are dragons." With the voyage of Columbus, we lost both our fear of the geographic frontier and our innocence. We accept that knowledge can generally overpower fear; but we have also learned that the application of new knowledge often has a dark side that can lead to brutality and disaster. The discovery of America, for example, led to unforeseen value conflicts of justice and fairness involving native Americans that were "resolved" only by their merciless subjugation and genocidal destruction. The Columbus metaphor is a powerful one, one that emphasizes both the need to confront mythical dragons with knowledge, and the need to anticipate and plan for the real monsters: the value conflicts that new knowledge produces. Perhaps nowhere is the promise of benefit and the risk of harm so great as in genetic research. The plan to map and sequence the three billion base pairs that make up the genetic blueprint of a human being — the Human Genome Initiative — provides an opportunity to examine the relationship between science and society.¹ How can scientists and social policymakers work together to maximize the benefits of this project while minimizing its dangers?

I. MONSTER MYTHOLOGY

Since at least Elizabethan times, English literature has reflected a fascination with stories of scientists and physicians who have attempted to change the attributes of humankind, and the monsters their attempts have

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¹ For the most complete description of the Human Genome Initiative to date, see OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, *MAPPING OUR GENES: GENOME PROJECTS: HOW BIG, HOW FAST?* (1988) [hereinafter *MAPPING OUR GENES*]. For a general description of the regulation of genetic research see, Symposium, *Biotechnology and the Law: Recombinant DNA and the Control of Scientific Research*, 51 S. CAL. L. REV. 969-1554 (1978).

created. Shakespeare set the tone and provided the language and setting for much of this cautionary literature. *The Tempest*, which is set on an island, forces us to confront the meaning of the natural. The lowly and grotesque Caliban often is seen as a monster, as when Trinculo says of him, "That a monster should be such a natural!"² If we see nature as orderly, then the disorderly and deformed Caliban must be a monster.³

When Prospero's daughter Miranda, who has grown up with Caliban and the spirits but has seen no other humans, sees the shipwrecked party from Italy, she exclaims of them:

O, wonder!

How many goodly creatures are there here!

How beauteous mankind is! O brave new world

That has such people in't!⁴

At the end of the play, as Prospero prepares to return to the real world and reclaim his place as Duke of Milan, he breaks his magic wand. This gesture has properly been seen as the author's commentary on the relationship between art and life: art, or at least an enchanted island, is no place for man to live, "but rather a place through which we pass in order to renew and strengthen our sense of reality."⁵

Huxley, of course, took the title of his most famous work on the social implications of the new genetics, *Brave New World*, from Miranda's description. Between Shakespeare and Huxley are at least three other writers who have altered our collective consciousness so that the creatures they created stir our minds when we contemplate modifying modern man: Mary Shelley, H.G. Wells, and Robert Louis Stevenson.

Mary Shelley's masterpiece, *Frankenstein*, has become the metaphor for all scientific attempts to create life.⁶ In her gothic novel, Victor Frankenstein is obsessed with creating life from a construction of dead body parts. Shelley does not explain how Victor was able to "infuse a spark of being into the lifeless thing," but she does describe Victor's emotions upon

² W. SHAKESPEARE, *THE TEMPEST* 87 (New American Library ed. 1964).

³ Langbaum, *Introduction to id.*, at xxv.

⁴ W. SHAKESPEARE, *supra* note 2, at 115.

⁵ *Id.* at xxxiv.

⁶ See, e.g., Gaylin, *The Frankenstein Factor*, 279 *NEW ENG. J. MED.* 665 (1977).

seeing "the dull yellow eye of the creature open":

His limbs were in proportion, and I had selected his features as beautiful. Beautiful! Great God! His yellow skin scarcely covered the work of muscles and arteries beneath; his hair was of a lustrous black, and flowing; his teeth of a pearly whiteness . . .⁷

But Victor's burst of emotion at achieving his goal quickly changes to horror as he gazes at the creature's "watery eyes . . . his shrivelled complexion and straight black lips": "now that I had finished, the beauty of the dream vanished, and breathless horror and disgust filled my heart."⁸

Victor leaves his laboratory to sleep, and the creature escapes. The remainder of the novel deals with the creature, which is never given a name but is simply referred to as "the monster," and its relationship to Victor. Indeed, it seems most reasonable to consider the monster either as Victor's alter ego, or as a projection of his inner thoughts made flesh. Perhaps this is why we often think of the monster, instead of its creator, as Frankenstein. Victor's creation eventually kills his young nephew William, his friend Clerval, his wife Elizabeth, and, indirectly, Victor himself.

At one point in the story, the monster convinces Victor to create a wife for him. In this scene, Victor is seen as God the creator, and the monster as his Adam, or alternatively, as Lucifer, the fallen angel. But having constructed the monster's would-be mate on a remote island, Victor decides he cannot give her life for fear that she and the monster might propagate a "race of devils" that would "make the very existence of the species of man a condition precarious and full of terror."⁹ Victor consequently tears the female's body apart while the monster looks on, letting out a "howl of devilish despair and revenge . . ."¹⁰ This scene, as much as any other, focuses the theme of the novel: the scientist's simultaneous capacity for creation and destruction.¹¹

In *The Tempest*, Shakespeare sees the chaos of nature as a constructive

⁷ M. SHELLEY, *FRANKENSTEIN* 56 (New American Library ed. 1963).

⁸ *Id.*

⁹ *Id.* at 158.

¹⁰ *Id.* at 159.

¹¹ The novel's subtitle, "The Modern Prometheus," emphasizes this theme in its reference to the mythic Titan who aided man by stealing fire from the gods, but also harmed man by alienating the gods.

force that helps renew social order. Mary Shelley's vision seems different: the orderliness of scientific research produces chaos and ultimately death. As one critic has put it, a fitting epigraph for *Frankenstein* may be the taunt of a Fury to the Prometheus of Percy Shelley, Mary's husband: "And all best things are thus confused to ill."¹²

The dark side of an individual's personality also takes on its own life in Robert Louis Stevenson's *Dr. Jekyll and Mr. Hyde*.¹³ Dr. Jekyll determines to discover what divides good and evil in human nature, and compounds a drug to suppress his good nature, and let his evil side (Mr. Hyde) dominate. Dr. Jekyll assures us that though his nature was split, he was not:

Though so profound a double-dealer, I was in no sense a hypocrite; both sides of me were in dead earnest; I was no more myself when I laid aside restraint and plunged in shame, than when I laboured, in the eye of day, at the furtherance of knowledge or the relief of sorrow and suffering. . . . With every day, and from both sides of my intelligence, the moral and the intellectual, I thus drew steadily nearer to that truth, by whose partial discovery I have been doomed to such a dreadful shipwreck: that man is not truly one, but truly two.¹⁴

For our purposes, the murderous Mr. Hyde can be thought of as a monster in the lineage of Frankenstein's monster. Like that monster (and Caliban) he is a misshapen creature, "hardly human" who gives "an impression of deformity without any nameable malformation."¹⁵ Although the stages are different in length, Jekyll goes through the same stages as Victor Frankenstein with his monster: he "creates" Hyde, openly admires him, flees from him, and ultimately does what he can to bring about his destruction. Neither creator can control his "monster."

Written ten years after *Dr. Jekyll and Mr. Hyde*, and another ten years before the word "gene" was coined,¹⁶ H.G. Well's *The Island of Dr.*

¹² Bloom, *Afterword* to M. SHELLEY, *supra* note 7, at 223. See generally M. SPARK, MARY SHELLEY 153-78 (1987).

¹³ R.L. STEVENSON, *DR. JEKYLL AND MR. HYDE* (Bantam ed. 1981). See also S. KING, *THE DARK HALF* (1989).

¹⁴ *Id.* at 79.

¹⁵ *Id.* at 18.

¹⁶ The word "gene" first made its appearance in 1909. In 1911, Wilhelm Johannsen first "pro-

*Moreau*¹⁷ brings us into the twentieth century. Like Prospero before him, Dr. Moreau is depicted as a god who rules over his island. And like *Frankenstein*, the story involves the making of human beings by non-natural means. Moreau has discovered how to combine transplant surgery and drugs to transform animals into creatures with a human-like shape and a human-like brain. His animal-men talk, and reject their animal (natural) ways. But they are grotesque in appearance, and their transformation is not permanent. When the shipwrecked Charles Prendick, the narrator of the tale, accuses Moreau of creating "an abomination," Moreau replies simply, "To this day I have never troubled about the ethics of the matter. The study of Nature makes a man at last as remorseless as Nature. I have gone on, not heeding anything but the question I was pursuing."¹⁸

Eventually the creatures turn on Moreau and kill him, and the remainder of the tale relates the "slow and inevitable" reversion of the creatures from human to animal:

Of course these creatures did not decline into such beasts as the reader has seen in zoological gardens — into ordinary bears, wolves, tigers, oxen, swine, and apes. There was still something strange about each; in each Moreau had blended this animal with that; one perhaps was ursine chiefly, another feline chiefly, another bovine chiefly, but each was tainted with other creatures — a kind of generalised animalism appeared through the specific dispositions. And the dwindling shreds of the humanity still startled me every now and then, a momentary recrudescence of speech perhaps, an unexpected dexterity of the fore feet, a pitiful attempt to walk erect.¹⁹

Their loss of speech was the ultimate sign of their loss of humanity. The story, of course, has many modern parallels. As Brian Aldiss put it in 1988, "The spirit of Dr. Moreau is alive and well and living in these

posed the terms 'gene' and 'genotype' . . . to be used in the science of genetics. The 'gene' is nothing but a very applicable little word, easily combined with others, and hence it may be useful as an expression for the 'unit-factors,' 'elements' or 'allelomorphs' in the gametes, demonstrated by modern Mendelian researches." 6 OXFORD ENGLISH DICTIONARY 428 (2d ed. 1989).

¹⁷ H.G. WELLS, *THE ISLAND OF DR. MOREAU* (New American Library ed. 1988).

¹⁸ *Id.* at 75.

¹⁹ *Id.* at 129.

United States. These days, he would be state-funded."²⁰

Aldous Huxley's *Brave New World*²¹ provides an example of how the state could use new-found techniques, including those of genetics, to keep its citizens controlled and contented. The novel is not about scientific research and discovery, but about the application of knowledge to specific governmental goals. Huxley's work presaged the Nazi eugenics program, with its rigid biologically-based class system. In *Brave New World*, natural human reproduction has been abolished; all reproduction is done artificially in state hatcheries and conditioning centers. The key to social control is the "Bokanovsky Process" in which a single embryo is stimulated to divide into ninety-six identical copies. These ninety-six embryos (or all the survivors, seventy-two being the average) are artificially gestated together under identical conditions designed to produce four basic classes of workers: Gammas, Deltas, Epsilons, and Alphas. Specific "batches" are conditioned to perform specific tasks and to love performing them. As the Director of the Hatcheries put it, conditioning "is the secret of happiness and virtue — liking what you've *got* to do. All conditioning aims at that: making people like their unescapable social destiny."²²

The resulting society is compactly described by Mustapha Mond, the Resident World Controller for Western Europe, to a man who had been brought back to "civilization" from the reservation, and who is known as "the Savage." He explains to the Savage why it would be impossible to write *Romeo and Juliet* or *Othello* now:

Because our world is not the same as Othello's world. You can't make flivvers [inexpensive autos] without steel — and you can't make tragedies without social instability. The world's stable now. People are happy; they get what they want, and they never want

²⁰ Aldiss, *Afterword* to H.G. WELLS, *supra* note 17, at 142. See also Ringel, *Genetic Experimentation: Mad Scientists and the Beast*, 2 J. OF FANTASTIC IN THE ARTS 64, 74-75 (1989) ("Many of us . . . prefer our mad genetic experimenters to remain fiction — not agribusiness as usual.").

²¹ A. HUXLEY, *BRAVE NEW WORLD* (1932).

²² *Id.* at 10 (italics in original). The caste system is rigid, but members of each caste are conditioned to believe both that they are in the preferable caste, and that members of all the other castes are nonetheless indispensable to their own happiness. The conditioning is based on slogans repeated over and over during sleep cycles in infancy and gestation. Some examples: "Every one works for every one else. We can't do without any one. Even Epsilons are useful. We couldn't do without Epsilons." *Id.* at 49. And: "When the individual feels, the community reels." *Id.* at 62. A view of the caste system in contemporary U.S. culture is presented in Flannery O'Connor's short story, *Revelation*. F. O'CONNOR, *THE COMPLETE STORIES* 488-509 (1971).

what they can't get. They're well off; they're safe; they're never ill; they're not afraid of death; they're blissfully ignorant of passion and old age; they're plagued with no mothers or fathers; they've got no wives, or children, or lovers to feel strongly about; they're so conditioned that they practically can't help behaving as they ought to behave. And if anything should go wrong, there's *soma*.²³

Huxley thus seems to reject Shakespeare's view of art and order being in harmony, and suggests that at least some disorder is necessary to produce real art — order itself produces only sterile contentment.²⁴

These five works of art from three different centuries help frame the emotional and intellectual debate about the ends of genetic research today. They keep us centered on the critical issues: What does it mean to be human, and how can the human condition be enhanced? Some scientists continue to insist that these questions are none of science's concern. They insist that their job is simply to explore the world in search of new knowledge; society's job is to use, misuse, apply, or misapply that knowledge.²⁵ The Human Genome Initiative provides us with a contemporary megaproject that can be used as a vehicle to explore the proper relationship between science and society as science seeks to understand the genetic basis of human characteristics.

II. THE HUMAN GENOME INITIATIVE

The Human Genome Initiative is the effort to map and sequence the approximately three billion base pairs of nucleotides that make up the twenty-three different human chromosomes that compose the human

²³ A. HUXLEY, *supra* note 21, at 149 (italics in original).

²⁴ Of course, if chaos produces art, and art in turn has a beneficial impact on society, then societal chaos may actually be "orderly" in that it may help make cultural and political change determinative but in a manner that defies our current understanding. See, e.g., I. PRIGOGINE & I. STENGERS, *ORDER OUT OF CHAOS* (1984). For a more accessible description of chaos theory in nature see J. GLEICK, *CHAOS* (1987) and Pool, *Is It Chaos, or Is It Just Noise?*, 243 *SCIENCE* 25-28 (1989).

²⁵ See, e.g., Koshland, *The Molecule of the Year*, 246 *SCIENCE* 1541, 1541 (1989) ("The new knowledge . . . can be used for good or evil, can be distributed fairly or unfairly. The challenge to science is to generate the new discoveries. The challenge to society is to use those discoveries for the betterment of all.").

"genome." The biology of DNA is well described elsewhere,²⁶ so for the purposes of this paper's preliminary exploration of the social policy issues raised by the project, it is only necessary to know a few basic definitions and facts. The first is that the term "genome" refers to the entire complement of genetic material in the set of chromosomes of a particular organism.²⁷ Chromosomes are composed of genes (50,000 to 100,000 in a human being), which in turn are composed of deoxyribonucleic acid (DNA), the chemical carrier of genetic information.²⁸ DNA is made of nucleotides, which are found in two linear strands wrapped around each other in the form of a double helix.²⁹ The DNA strands themselves are composed of four nucleotides: adenosine (A), guanosine (G), cytidine (C) and thymidine (T). The two strands of DNA are bound together by weak bonds between base pairs of the nucleotide: A's only bind with T's, and G's only bind with C's. The size of the genome is usually expressed as the total number of such base pairs; there are approximately three billion in the twenty-four different kinds of human chromosomes, the twenty-two different autosomal chromosomes, and the X and Y chromosomes that determine sex.³⁰

Genetic mapping is the process of assigning genes to specific chromosomes. Genetic linkage maps determine where one genetic locus is relative to another on the basis of how often they are inherited together. A genetic locus is an identifiable area or "marker" on a chromosome, the presence of which indicates that a specific trait (such as eye color or blood type) will be expressed by the gene.³¹

The physical map of greatest interest to scientists is one that has the highest possible resolution.³² This is the complete nucleotide sequence of the human genome and is why the project is often referred to as "mapping and sequencing" the human genome. Current methods of sequencing remain laborious, and the complete sequencing of the human genome will almost certainly require major innovations in sequencing technology.

²⁶ *E.g.*, MAPPING OUR GENES, *supra* note 1, at 21-24.

²⁷ *Id.* at 21.

²⁸ *Id.* at 24.

²⁹ S. ELIAS & G. ANNAS, REPRODUCTIVE GENETICS AND THE LAW 1-6 (1987).

³⁰ MAPPING OUR GENES, *supra* note 1, at 24. Each human has forty-six paired chromosomes, half of them (a haploid set) from each parent.

³¹ *Id.* at 26-27.

³² *Id.* at 30.

In the United States there is no single human genome project. Three major groups are funding various aspects of an overall "initiative" on genome mapping: the National Institutes of Health (NIH), the Department of Energy (DOE), and the Howard Hughes Medical Institute.³³ Other organizations are doing work on the genome in other countries, and a private organization, the Human Genome Organization (HUGO), has proposed that it act as an international coordinator among the groups in the different countries pursuing this project.³⁴

A map is useful in getting you where you want to go, but doesn't tell you anything about what it will be like when you get there. For example, a map of Boston will tell you where streets are located, but will not tell you who lives on them or what types of activities occur on various streets. Similarly, a map of the human genome will tell you where genes are located on chromosomes, but will not disclose their functions. Analyzing the information on the map of the human genome will be yet another, more complex project. As the recent discovery of the gene for cystic fibrosis has demonstrated, much progress can be made in identifying specific genes without having the map of the genome itself.³⁵

The complexity of putting the map together, however, should not be underestimated. MIT geneticist Eric Lander has described it by using a book reconstruction analogy:

It's as if I took six sets of the *Encyclopaedia Britannica* and shredded them, and spread the pieces all over the floor, and asked you to reconstruct the books. How do you do that? You look for pages that overlap, so you need multiple copies of the books. You would spend a year or two or three just gluing these copies together in the correct order. And then you have to read the thing. *That's* the genome project.³⁶

³³ *Id.* at 7.

³⁴ McKusick, *Mapping and Sequencing the Human Genome*, 320 NEW ENG. J. MED. 910, 913 (1989).

³⁵ Finding the cystic fibrosis gene cost approximately \$120 million (most supplied by the Cystic Fibrosis Foundation), and the area that has been mapped only codes about 75% of all cystic fibrosis. Cystic fibrosis occurs in approximately 1 in 2,500 live births. See Lemna, Feldman, Kerem, Fernbach, *et al.*, *Mutation Analysis for Heterozygote Detection and the Prenatal Diagnosis of Cystic Fibrosis*, 322 NEW ENG. J. MED. 291 (1990); Roberts, *To Test, or Not to Test?*, 247 SCIENCE 17, 18 (1990).

³⁶ Hall, *James Watson and the Search for Biology's 'Holy Grail'*, SMITHSONIAN, Feb. 1990, at 47 (emphasis in original).

The Office of Technology Assessment of the United States Congress summarized five arguments that scientists give to support sequencing entire genomes, which also can be applied to the human genome:

- The information in a genome is the fundamental description of a living system . . . and so is of fundamental concern to biologists.
- Genome sequences provide a conceptual framework within which much future research in biology will be structured [such as] . . . control of gene expression.
- [N]early 90 percent of total DNA content [is likely to have no function] . . . Without a complete DNA sequence of several genomes, it will be impossible to determine whether such sequences have meaning or are ancestral "junk" sequences.
- Genome sequences are important for addressing questions concerning evolutionary biology. The reconstruction of the history of life on this planet, the definition of gene families . . . and the search for a universal ancestor all require an understanding of the organization of genomes.
- Genomes are natural information storage and processing systems; unraveling them may be of general interest to computer and physical scientists.³⁷

James Watson, the co-discoverer of DNA, has been named to head the NIH Human Genome Initiative. Watson is enthusiastic about this project, stating that he expects that "[w]hen finally interpreted . . . the genetic messages encoded within our DNA molecules will provide the ultimate answers to the chemical underpinnings of human existence."³⁸ He describes the human genome project as consisting of four phases:

One, we map all the genes; two, we sequence all the genes, or break them down into their chemical components, which is the ultimate map; three, we distribute this information to scientists around the world through 'in-formatics' that are easily understood and useful; and, fourth, we build in ethical safeguards so that the information is properly used and not exploited to discriminate against anyone.³⁹

³⁷ MAPPING OUR GENES, *supra* note 1, at 57.

³⁸ Breo, *DNA Discoverer James Watson Now Dreams of Curing Genetic Diseases*, 262 JAMA 3340, 3343 (1989).

³⁹ *Id.* In early 1990 Watson announced that mapping the genome would take about five years, and that an all-out drive for end-to-end sequencing would not begin until after that task was completed. Cotes, *Keeping Them Guessing*, 343 NATURE 579 (1990).

The uniqueness of the Human Genome Initiative is not its quest for knowledge. The history of science is filled with little else. What is unique is an understanding at the outset that serious social policy and ethical issues are raised by the research, and that steps ought to be taken now to try to assure that the benefits of the project are maximized and the potential dark side is minimized.

III. THE LEGAL AND ETHICAL ISSUES RAISED BY THE HUMAN GENOME INITIATIVE

To oversimplify somewhat, there are three levels of issues that the Human Genome Initiative raises: individual/family, society, and species. Almost all work on genetics to date has involved the individual/family level where questions of genetic screening and counseling have center stage. Negligence in failing to offer or to perform genetic screening tests properly has resulted in lawsuits for wrongful birth and wrongful life; and standards for genetic screening and counseling have been set by professional organizations.⁴⁰

The level two issues implicate society more directly. In the Human Genome Initiative there are three major societal issues: population-based genetic screening, resource allocation and commercialization, and eugenics. More specifically, the questions raised by the project are to what uses its fruits should be put to screen groups of people, such as applicants for the military, government workers, immigrants, etc.; what priority should the genome project have for federal funding and what role should patenting laws play; and finally, should we attempt to use the new genetics to improve our citizens, either by trying to eliminate specific genetic diseases or by enhancing desirable traits?⁴¹

The level three issues are somewhat more speculative, and involve the way in which a genetic view of ourselves could change the way we think about ourselves.⁴² This level raises recurrent philosophical questions in-

⁴⁰ See generally S. ELIAS & G. ANNAS, *supra* note 29, at 33-142.

⁴¹ Annas, *Who's Afraid of the Human Genome?*, 19 HASTINGS CENTER REP., July/Aug. 1989, at 19, 19-21.

⁴² See generally L. TRIBE, *CHANNELING TECHNOLOGY THROUGH LAW* (1973); Tribe, *Technology Assessment and the Fourth Discontinuity: The Limits of Instrumental Rationality*, 46 S. CAL. L. REV. 617 (1972).

volving determinism, reductionism, normalcy, and the meaning of health and disease.

This brief cataloging of the major issues raised on each level suggests that there are probably no *unique* issues raised by the Human Genome Initiative. On the other hand, this project raises *all* of the issues in a much more focused manner (certainly a difference in degree if not in kind), and the fact that all of these issues are implicated in the project may itself make the project societally unique.

A. *Level One (Individual/Family) Issues*

Genetic screening and counseling are techniques that have been in widespread use in the United States for more than two decades. Stated concisely, "[g]enetic counseling is the process whereby an individual or family obtains information about a real or possible genetic problem."⁴³ Counseling is usually directed primarily toward couples deciding whether to have children based on the couple's risk of having a child with a genetic handicap; towards pregnant women concerning the existence of genetic tests to determine the status of the fetus; and towards parents of newborns concerning the genetic condition of their child.

Genetic screening bridges level one and level two issues because it is primarily a public health endeavor that actively seeks out asymptomatic people, many of whom would not otherwise seek medical care or discover their condition. It is primarily a "search in a population for persons possessing certain genotypes that (1) are already associated with disease or predisposed to disease, (2) may lead to disease in their descendants, or (3) produce other variations not known to be associated with disease."⁴⁴ Individuals in the first category are identified for treatment, those in the second can receive counseling about their reproductive options, and those in the third are primarily identified for research purposes to help determine the genetic makeup of populations. Screening may target specific groups such as pregnant women, newborns, or married couples planning to have children.

⁴³ S. ELIAS & G. ANNAS, *supra* note 29, at 34.

⁴⁴ NATIONAL ACADEMY OF SCIENCES, *GENETIC SCREENING: PROGRAMS, PRINCIPLES, AND RESEARCH* 9 (1975).

Since there have been large-scale genetic screening and counseling programs for such diseases as Tay-Sachs, sickle cell disease, PKU, and neural tube defects, it might be supposed that the major social policy issues raised by such screening have been solved. This supposition would be incorrect. This in part results from the fact that each genetic disease has unique characteristics and thus poses unique issues. For example, some diseases occur most frequently in specific racial or ethnic groups, raising potential issues of discrimination and stigmatization.⁴⁶ Other screening tests, such as those for neural tube defects, can be done only on pregnant women, and abortion is the only "treatment."⁴⁸ Still others can be performed only on newborns, and screening for conditions such as PKU that require immediate treatment to prevent harm has been made mandatory by almost all states.⁴⁷

Although none of the major issues raised by past genetic screening and counseling cases have been solved, the major factors to be considered before initiating a screening program have been identified: (1) the frequency and severity of the condition; (2) the availability of treatment of documented efficacy; (3) the extent to which detection by screening improves the outcome; (4) the validity and safety of the screening tests; (5) the adequacy of resources to assure effective screening and counseling follow-up; (6) the costs of the program; and (7) the acceptance of the screening program by the community, including physicians and the public.⁴⁸

This list primarily relates to the scientific validity and cost/benefit analysis of the testing procedure. In addition, two major ethical and legal issues are implicit in all genetic screening programs: autonomy and confidentiality. Autonomy requires that all screening programs be voluntary, and that consent to them is sought only after full information concerning the implications of a positive finding is both disclosed and understood.

⁴⁶ See S. ELIAS & G. ANNAS, *supra* note 29, at 76-78 and sources cited therein.

⁴⁶ For a general discussion of routine prenatal screening standards with specific reference to neural tube defects, see Annas & Elias, *Maternal Serum AFP: Educating Physicians and the Public*, 75 AM. J. PUB. HEALTH 1374 (1985).

⁴⁷ See S. ELIAS & G. ANNAS, *supra* note 29, at 54-57, 77, and sources cited therein.

⁴⁸ *Id.* at 54. See also N.A. HOLTZMAN, *NEWBORN SCREENING FOR GENETIC-METABOLIC DISEASES: PROGRESS, PRINCIPLES AND RECOMMENDATIONS* (1977). These factors are currently at the center of discussion about initiating cystic fibrosis screening. See *supra* note 35; Elias, Annas & Simpson, *Carrier Screening for Cystic Fibrosis: Implications for Obstetric and Gynecologic Practice*, 163 AM. J. OB. & GYN. — (forthcoming 1990).

Confidentiality requires that the finding not be disclosed to anyone else without the individual's consent.⁴⁹ While not a genetic disease, HIV infection has provided an opportunity to see how widespread discrimination against individuals with a particular condition demands that testing be voluntary and that the results be kept confidential to protect the rights of individuals.⁵⁰

Provided that testing remains voluntary, and that the results are disclosed only with the individual's permission, genetic testing based on one's genome raises questions only of degree rather than kind. The degree is that instead of one or even hundreds of conditions that can be screened for, there may be thousands. Perhaps even more important, scientists may find that certain genes predispose a person to specific illnesses, such as breast cancer or Alzheimer's disease. This information may be very troubling to individuals, but will be of great interest to health insurance companies and employers.⁵¹

In the employment setting, for example, it has already been suggested that five principles should guide legislators, regulators, and professional groups in setting guidelines for medical screening: (1) medical inquiries of employees should be limited to job-related information; (2) only tests that are safe and of proven efficacy should be used; (3) applicants and employees should be informed of all medical tests in advance, told when any employment decision will be based on test results, and given the results; (4) intra-company and extra-company disclosure of medical records must be controlled and confidentiality assured; and (5) comprehensive, consistent, and predictable handicap discrimination legislation should be enacted.⁵² These worthy principles should be supplemented with three other principles directed at employers: (1) ethical issues involving screening should be fully explored before a screening program commences; (2) screening should be done only on an individual who gives informed consent; and (3) counseling should be available both before and after screening, and the resources for any reasonable intervention that can benefit the

⁴⁹ See S. ELIAS & G. ANNAS, *supra* note 29, at 48-49 and sources cited therein.

⁵⁰ See, e.g., Gostin, *The Politics of AIDS: Compulsory State Powers, Public Health, and Civil Liberties*, 49 OHIO ST. L.J. 1017 (1989).

⁵¹ Huntington's disease provides a possible model for analyzing the issues raised by such testing.

⁵² M. ROTHSTEIN, *MEDICAL SCREENING AND THE EMPLOYEE HEALTH COST CRISIS* 221 (1989). See also Ashford, *Medical Screening in the Workplace: Legal and Ethical Considerations*, 1 SEMINARS IN OCCUPATIONAL MED. 67 (1986).

individuals screened should be in place and available to them before screening is offered.⁵³

We have so far managed to develop genetic screening and counseling as tools that permit use by individuals and families as they see fit. This approach has followed the "medical model" of the beneficent doctor-patient relationship, which is a model of mutual consent in which decisions are made for benefit of the patient. This model has served well to date in expanding the reproductive options of individuals. Level two concerns move from the individual to considerations about society itself.

B. Level Two (Societal) Issues

Societal issues involved in the genome cluster in three areas: population-based screening, resource allocation and commercialism, and eugenics. Of these, the first issue overlaps with level one concerns (since population screening can be used to identify individuals that need help), and the last is both unique and troubling. All merit discussion.

Population-based screening has already been discussed in level one. It can help eliminate a genetic condition, or simply identify the incidence of a genetic condition in a population or the presence of a genetic condition in an applicant for a particular benefit (employment, insurance, immigration, etc.). As previously discussed, autonomy and confidentiality are the major legal issues involved, and population-based screening becomes problematic primarily when it is mandatory and the results are made known to others without consent. The other two areas involving societal issues are more uniquely "societal."

The issue of resource allocation has at least three aspects. The first is the obvious one — what percentage of the nation's research budget should be devoted to the Human Genome Initiative? Answering this question requires us to consider how research priorities are set in science, and who should set them. With the federal government making a major commitment to this program (currently approximately \$100 million annually to NIH and DOE),⁵⁴ should Congress appropriate funds directly to the gen-

⁵³ S. ELIAS & G. ANNAS, *supra* note 29, at 54.

⁵⁴ See Marwick & Merz, *Gene Mappers Form Collaborations*, 260 JAMA 2477 (1988); Palca,

ome project (as it is currently doing), or should the program compete directly with other proposed research projects and be peer-reviewed?

The second aspect involves making the benefits of the Genome Initiative available to all those who want them. This possibility raises at least two questions. The first is the issue of commercialism — who “owns” and can patent the products that are produced by the Genome Initiative?⁵⁵ Because much of this research is federally-funded, should its benefits be in the public domain? Or should individual companies and scientists be able to patent or copyright maps and sequences of specific areas of human genome in order to encourage mapping research? Issues of patents are important, but are ultimately no different than those issues posed by patenting AZT or by patenting a cell line developed from a patient’s diseased spleen.⁵⁶ The other issue can be summed up in three words — national health insurance. Should the genetic tests and their follow-up procedures be made part of a “minimum benefit package” under national health insurance (or some other scheme for universal access), or should they be available only to those people who can pay for them with private funds? This question, of course, is also not unique to the genome project; society must confront it with every new medical technology.⁵⁷

The third aspect of the resource allocation issue is probably the most intrinsically interesting. It involves determining the balance of resource priorities between the amount spent on identifying and treating genetic diseases, and the amount spent directly on other conditions that cause disease, such as poverty, drug and alcohol addiction, lack of housing, poor education, and lack of access to decent medical care. In a country like the United States, is it ethical or rational to develop medical technologies that large segments of the population would not have access to today if they were available, or to develop technologies that, even if universally available, would be useful only to a few individuals?⁵⁸

Genome Projects Are Growing Like Weeds, 245 SCIENCE 131 (1989).

⁵⁵ See, e.g., Roberts, *Who Owns the Human Genome?*, 237 SCIENCE 358 (1987).

⁵⁶ For an excellent introduction to the issues involving commercialism in the biotechnology field, see OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, *COMMERCIAL BIOTECHNOLOGY: AN INTERNATIONAL ANALYSIS* (1984); OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, *NEW DEVELOPMENTS IN BIOTECHNOLOGY: OWNERSHIP OF HUMAN TISSUES AND CELLS* (1987).

⁵⁷ See generally D. CALLAHAN, *WHAT KIND OF LIFE?* (1990).

⁵⁸ See generally Mariner, *Equitable Access to Biomedical Advances: Getting Beyond the Rights Impasse*, 21 CONN. L. REV. 571 (1989).

What is the social impact of putting the spotlight on a project like the Human Genome Initiative? Could the fact that we are vigorously pursuing this project lead us to de-emphasize environmental pollution, work site hazards, and other major social problems that cause disease, because we someday hope to find a "genetic fix" that would permit humans to "cope" with these unhealthy conditions?⁵⁹ Given the fact that many of the homeless are mentally ill, with conditions that may be genetically determined and treatable, it has been strangely suggested that the fruits of the human genome project may help solve society's homelessness problem.⁶⁰ Finally, the Genome Initiative has already led to speculation about its role in international economic competition and to suggestions that the Japanese are not playing fair and should be cut out of any international information exchange on the genome.⁶¹ What role does, or should, international economic competition play in deciding how much federal funding should go to the Genome Initiative?

The third level two issue, and the most important one, concerns eugenics. This issue is perhaps the most difficult to address because of the highly emotional reaction many individuals have to even the mention of the Nazis' racist genocide, which was based on a eugenic program founded on a theory of "racial hygiene."⁶² Although repugnant, the Nazi experience and legacy demand careful study to determine what led to it, why scientists and physicians supported and collaborated in developing its theory and in making possible its execution, and how it was implemented by a totalitarian state. In this regard our own national experience with racism, sterilization, and immigration quotas will have to be reexamined. In so doing, we are likely to rediscover the powerful role of economics in

⁵⁹ See generally A. ETZIONI, *GENETIC FIX* (1973).

⁶⁰ See, e.g., Koshland, *Sequences and Consequences of the Human Genome*, 246 *SCIENCE* 189, 189 (1989). In his words:

The benefits to science of the genome project are clear. Illnesses such as manic depression, Alzheimer's, schizophrenia, and heart disease are probably all multigenic and even more difficult to unravel than cystic fibrosis. Yet these diseases are at the root of many current societal problems. The costs of mental illness, the difficult civil liberties problems they cause, the pain to the individual, all cry out for an early solution that involves prevention, not caretaking. To continue the current warehousing or neglect of these people, many of whom are in the ranks of the homeless, is the equivalent of providing iron lungs to polio victims at the expense of working on a vaccine.

⁶¹ See, e.g., Roberts, *Watson Versus Japan*, 246 *SCIENCE* 576-78 (1989).

⁶² See R. LIFTON, *THE NAZI DOCTORS* (1986); B. MULLER-HILL, *MURDEROUS SCIENCE* (1988); R. PROCTOR, *RACIAL HYGIENE* (1988).

driving our own views of evolution (in the form of social Darwinism) and who should propagate.

The Supreme Court, for example, wrote in 1927, with clear reference to World War I, that eugenics by involuntary sterilization of the mentally retarded was constitutionally acceptable based on utilitarianism:

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind.⁶³

Such thinking may seem like ancient history, but in 1988 the United States Congress Office of Technology Assessment (OTA) developed a similar theme in discussing the "Social and Ethical Considerations" raised by the Human Genome Initiative:

Human mating that proceeds without the use of genetic data about the risks of transmitting diseases will produce greater mortality and medical costs than if carriers of potentially deleterious genes are alerted to their status and encouraged to mate with noncarriers or to use artificial insemination or other reproductive strategies.⁶⁴

The likely primary reproductive strategy, mentioned only in passing in the report, will be genetic screening of human embryos, already technically feasible, but not nearly to the extent possible once the genome is better understood. Such screening need not be required; people will want it, even insist on it, as their right. As OTA notes, "New technologies for identifying traits and altering genes make it *possible for eugenic goals to be achieved through technological as opposed to social control.*"⁶⁵ Huxley's *Brave New World*, rather than Orwell's *1984*, seems to be in our future.

Much excellent work on the history of medicine and its link to the

⁶³ *Buck v. Bell*, 274 U.S. 200, 207 (1927).

⁶⁴ See *MAPPING OUR GENES*, *supra* note 1, at 84.

⁶⁵ *Id.* (emphasis added).

eugenics movement is under way.⁶⁶ This scholarship should be made an integral part of any effort to understand the eugenics movement in the twentieth century. It will also be necessary to decide whether to use genetics to *improve* the species, and to articulate the philosophical and moral concerns entailed by a change in the direction of genetics from prevention and treatment to enhancement and "improvement."

So far, most writers have insisted that it is at least premature to follow the example of Dr. Moreau and try to *improve* upon the species, either by enhancing certain genetic characteristics, such as height, or by altering sex cells so that characteristics modified in an individual can be passed on to future generations.⁶⁷ Just as population-based screening provided a bridge between levels one and two, enhancing genetic traits provides a bridge between levels two and three.

C. Level Three (Species) Issues

Level three issues relate to the fact that powerful new technologies do not simply change what human beings can do, but also change the way humans think, especially about themselves. In this respect, maps may become particularly powerful thought transformers. Maps model reality and help us understand it. Columbus changed the shape of the world's map forever — from a flat chart to a spherical globe. Monsters could no longer either prowl or guard the edge of the world; there was no edge of the world. Copernicus and Vesalius published their great works in the same year, 1543. Copernicus' *On the Motions of Heavenly Bodies* made it clear that the earth rotated around the sun, not the other way around. The earth could no longer be seen as the "center" of the universe.

Vesalius' "maps" of the human anatomy may have been even more important metaphors for us, for in dissecting the human body Vesalius insisted that human beings could nonetheless be understood only as whole beings, *human* beings rather than as parts that can be fitted together to

⁶⁶ See *supra* note 62. Other notable scholars in this area include Christian Pross and William Seidelman.

⁶⁷ See, e.g., Anderson, *Human Gene Therapy: Scientific and Ethical Considerations*, 10 J. MED. & PHIL. 275, 283-90 (1985); Andrews & Mariner, *National Conference on Birth, Death, and Law*, 29 JURIMETRICS J. 403, 434 (1989).

manufacture life forms. For Vesalius, who shows twenty-one of seventy-three drawings in his *Fabrica*, and ten of twelve drawings in his *Epitome* as full figured humans, the emphasis is firmly on the person, even though the treatise is concerned with the person's body parts.⁶⁸ This portrayal starkly contrasts with the bar graph illustrations used by contemporary geneticists in "mapping" the genome, which are totally devoid of human reference, as though they were without life.⁶⁹ A similar lifeless reductionist phenomenon can be seen in the "maps" of areas of the human brain, which are said to correspond to various human emotions and the ability to think and conceptualize.⁷⁰ Does this reconceptualization of the human to a new "map" encourage us to travel into areas that could lead us to simultaneously misunderstand and demean what it is to be human?

What new human perspectives, or what new perspectives on humans, will a sequential map of the three billion base pairs of the human genome bring? The most obvious is that breaking "human beings" down into six billion "parts" is the ultimate in reductionism. James Watson himself has used such reductionist language in promoting the Human Genome Initiative. In his words, the project will provide "'the ultimate tool for understanding ourselves at the molecular level.'" ⁷¹ Just what this means is unclear, but Watson continues, "'How can we not do it? We used to think our fate was in our stars. Now we know, in large measure, our fate is in our genes.'" ⁷² Seeing our fate in our genes, of course, resonates with level two concerns: if genes determine our fate, then we can alter our fate by altering our genes. Maybe we really can look forward to the day when mental illness, and therefore at least some homelessness, can be prevented by genetic manipulation. Such a view raises most of the level three concerns.

The first concern is the consequence of viewing humans as an assem-

⁶⁸ See J. SAUNDERS & C. O'MALLEY, *THE ILLUSTRATIONS FROM THE WORKS OF ANDREAS VESALIUS* 49-227 (1950) (containing the full set of illustrations from both the *Fabrica* and the *Epitome*).

⁶⁹ But see McKusick, *The Human Genome Through the Eyes of a Clinical Geneticist*, 32 *CYTogenetics & CELL GENETICS* 7, 7-9 (1982) (author discusses Vesalius, but does not note this distinction in putting forth his genetic illustrations).

⁷⁰ For a discussion, see J. ECCLES, *EVOLUTION OF THE BRAIN: CREATION OF THE SELF* 84-85, 90-91 (1989).

⁷¹ Jaroff, *The Gene Hunt*, *TIME*, Mar. 20, 1989, at 63.

⁷² *Id.* at 67. See also Watson, *First Word*, *OMNI*, June 1990, at 6 (discussing the Human Genome Initiative).

blage of molecules, arranged in a certain way. The almost inevitable tendency of such a view is expressed in *Brave New World*. People could view themselves and each other as products that can be "manufactured" and subject to quality control measures. People could be "made to measure," both literally and figuratively. If people are so seen, we might try not only to manipulate them as embryos and fetuses, but also see the resulting children as products themselves. This possibility raises the current stakes in the debates about frozen embryos and surrogate mothers to a new height — if children are seen as products, the purchase and sale of the resulting children themselves, not only embryos, may be seen as reasonable.⁷³

Secondly, to the extent that genes are seen as more influential than environment, our actions may be viewed as genetically determined, rather than resulting from free will. Already we have witnessed an early example of this type of reasoning in the use of the "XYY defense." Individuals possessing the XYY karyotype were thought to be more prone to commit crime. Accordingly, individuals accused of crime who also had an extra Y chromosome argued that they should not be held responsible for their actions because their genetic composition predisposed them to crime.⁷⁴ This defense has been generally rejected, and in the few cases where it was accepted, the defendant was confined to a mental institution until "cured."⁷⁵ Of course, since it is impossible to remove the extra Y chromosome from any cell, let alone every cell, in one's body, a cure is not possible.

In addition to use in the criminal law, perhaps in the form of genetic screening followed by monitoring or "predelinquency detention," such genetic predispositions are likely to be used in education, job placement, and military assignments. For example, if intelligence in mathematics is found to be genetic, schools could use this information to track, grade and promote the "genetically gifted" in math classes.⁷⁶

⁷³ See Annas, *Making Babies Without Sex: The Law and the Profits*, 74 AM. J. PUB. HEALTH 1415, 1417 (1984).

⁷⁴ See Dershowitz, *Karyotype, Predictability and Culpability*, in GENETICS AND THE LAW 63 (A. Milunsky & G. Annas eds. 1976).

⁷⁵ *Id.* at 67-70. The most useful task for genetics in the criminal law may be its use in identification through DNA "fingerprinting." See Annas, *DNA Fingerprinting in the Twilight Zone*, 20 HASTINGS CENTER REP., Mar./Apr. 1990, at 35, and sources cited therein.

⁷⁶ See generally D. NELKIN & L. TANCREDI, *DANGEROUS DIAGNOSTICS* (1989).

Finally, we know that most diseases and abnormalities are social constructs rather than facts of nature. Myopia, for example, is well accepted, but obesity is not. There does not exist a "normal" or "standard" human genome that can be discovered, but one may be invented. If one is invented, what variations will society permit before an individual's genome is labelled "substandard" or "abnormal"? Moreover, what impact will such a construct of genetic normalcy have on society and on "substandard" individuals? For example, what variation in a fetus should prompt a couple to opt for abortion or a genetic counselor to suggest abortion? What variation should prompt a counselor to suggest sterilization? What interventions will society deem acceptable in an individual's life based on his or her genetic composition? Should health care insurance companies be able to disclaim financial responsibility for the medical needs of a child whose parents knew prior to conception or birth that the child would be born with a seriously "abnormal" genome? Should employers be able to screen out workers on the basis of their genomes? These and many other similar issues based on screening for single site genes exist today.⁷⁷ But the magnitude of screening possibilities that may result from an analysis of the map of the human genome will raise these issues to new heights, and will inevitably change the way we think about ourselves and what it means to be human.

What options exist for policymakers who want the benefits of the Human Genome Initiative but need to minimize or control the potential harms?

IV. STRATEGIES TO REGULATE GENETIC TECHNOLOGY

The good news about the Human Genome Initiative is that its proponents recognize the many social, ethical and legal issues this research raises. NIH's National Center for Human Genome Research, for example, has pledged to spend as much as one to three percent of its research budget on the study of the "ethical, social and legal issues that may arise from the application of knowledge gained from the Human Genome Initiative."⁷⁸ The Center has also formed an "Ethics Committee" and hired a

⁷⁷ See *supra* notes 46-49 and accompanying text.

⁷⁸ National Center for Human Genome Initiative, *Ethical, Legal and Social Implications of the*

philosopher to help formulate and deal with ethical issues. Likewise, the international Human Genome Organization (HUGO), made up of forty-two scientists from around the world, has formed an ethics committee and "intends to provide a forum for the discussion of ethical, social, commercial, and legal considerations relating to the genome project."⁷⁹

The issues that these groups, and others like them, will identify have been outlined. But what strategies exist to deal with them? As we have seen, English literature provides us with a rich backdrop from which to begin our consideration, but actual examples of successful regulatory intervention into either scientific research or technological application are much less plentiful. Nor have scientists and policymakers worked well together in the past. As C. P. Snow has noted, "Non-scientists tend to think of scientists as brash and boastful."⁸⁰ This attitude certainly is exemplified in the literature herein summarized, as is the view that scientists underestimate the danger in their work, and vastly overestimate its importance. Scientists, on the other hand, (with the possible exception of some involved in the Human Genome Initiative), tend to think of social policy and ethics as fields that "lag behind" science and cannot "keep up with" scientific progress and advancement. It is almost as if they believe that morality is a field of knowledge "in the charge of unidentified, but presumably rather incompetent experts."⁸¹ Experts in both fields have little experience with each other, and generally only meet in the courtroom or in the congressional hearing room. Scientists often then revert to the old slogan, "What is good for General Motors is good for the country," or more precisely, as James Watson has put it, "Science is good for society."⁸²

The challenge is to get beyond the literary archetypes, the stereotypes, and the clichés, and to work together to develop a coherent set of goals against which to judge scientific priorities and actions. Once these goals are agreed upon in an open and public forum, it will be reasonably easy to devise methods to accomplish them. A few such methods merit further discussion because they are the ones most likely to be used: moratoria and

Human Genome Initiative, 19 Fed. Bull. 12 (Jan. 26, 1990).

⁷⁹ McKusick, *supra* note 34, at 914.

⁸⁰ C.P. SNOW, *THE TWO CULTURES AND THE SCIENTIFIC REVOLUTION* 4 (1959).

⁸¹ T. ROSZAK, *THE MAKING OF A COUNTER CULTURE* 273 (1969).

⁸² Wade, *Gene Splicing Rules: Another Round of Debate*, 199 SCIENCE 33 (1978). He added, "We are being attacked [for recombinant DNA research] by everyone who doesn't have the guts to go ahead." *Id.*

bans, regulatory agencies, oversight committees, self-regulation, and private lawsuits.

A. *Moratoria and Bans*

Science has had almost no experience with moratoria, but one of the few that actually has been implemented is in the area of genetic research, specifically in the area of recombinant DNA (rDNA) research. It occurred in 1974 when, following approximately three years of discussion, a group of prominent genetic researchers called for a voluntary international moratorium on certain types of recombinant DNA research.⁸³ The moratorium, which has been termed "a rare, perhaps unique, event in the history of basic science research,"⁸⁴ was honored internationally from July, 1974 to February, 1975, at which time an international meeting of rDNA researchers was convened at Asilomar in California to consider the future of the moratorium. The result of the Asilomar meeting was agreement that "most of the work on the construction of recombinant DNA molecules should proceed," but that adequate biological and physical containment measures should be taken to prevent the creation and escape of potentially dangerous "newly created organisms."⁸⁵

At a Workshop on International Cooperation for the Human Genome Project held in Valencia in October, 1988, French researcher Jean Dausset suggested that the genome project posed great potential hazards that could open the door to Nazi-like atrocities. In an attempt to avoid such results, he suggested that the conferees agree on a moratorium on genetic manipulation of germ line cells, and a ban on gene transfer experiments in early embryos.⁸⁶ Reportedly, the proposal won wide agreement among the participants, but was watered down to a resolution calling for "international cooperation" after American participant Norton Zinder successfully argued that the group had no authority to make such a resolution

⁸³ For probably the best historical account of the recombinant DNA controversy, see Swazey, Sorenson & Wong, *Risks and Benefits, Rights and Responsibilities: A History of the Recombinant DNA Research Controversy*, 51 S. CAL. L. REV. 1019 (1978).

⁸⁴ *Id.* at 1026.

⁸⁵ Berg, Baltimore, Brenner, Roblin & Singer, *Asilomar Conference on Recombinant DNA Molecules*, 188 SCIENCE 991, 991 (1975).

⁸⁶ Roberts, *Carving Up the Human Genome*, 242 SCIENCE 1244, 1245-46 (1988).

stick.⁸⁷

Zinder was correct. A moratorium and ban on research that no one wants would, at this point, have only symbolic value — and negative symbolic value at that. It would signal that the scientists could handle the ethical issues alone, and could monitor their own work. It would tend to quiet the discussion of both germ line research and gene transfers in early embryos — both subjects that deserve wide public debate. But Dausset also had an important point. The Nazi atrocities grew out of the combination of a public health ethic that saw the abnormal as disposable, and a tyrannical dictatorship that was able to give the physicians and public health authorities unlimited power to put their bestial program into practice.

B. Regulatory Agencies

The combination of the Asilomar call for ending the moratorium, and its simultaneous call for biological and physical containment, led the federal government to develop specific guidelines governing the conduct of rDNA research done by facilities receiving federal funds. These guidelines primarily relied upon a series of biological and physical containment measures that increased as the risk of the rDNA experiment increased.⁸⁸ Compliance was to be supervised locally by an Institutional Biosafety Committee (IBC) which was requested, but not required, to open its meetings “to the public whenever possible, consistent with protection of privacy and proprietary interests.”⁸⁹

A few cities and states were not content to rely upon the federal guidelines and so developed their own. In 1976, Al Vellucci, the Mayor of Cambridge, Massachusetts, the home of both Harvard and MIT, as well as many private biotechnology firms, said, “They may come up with a disease that can’t be cured — even a monster. Is this the answer to Dr. Frankenstein’s dream?”⁹⁰ Recombinant DNA research is not, of course,

⁸⁷ *Id.*

⁸⁸ *Guidelines for Research Involving Recombinant DNA Molecules*, 48 Fed. Reg. 24,556 (1983).

⁸⁹ *Id.* at 24,560, § IV-B-2-f.

⁹⁰ PRESIDENT’S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *SPLICING LIFE: THE SOCIAL AND ETHICAL ISSUES OF GE-*

the answer to Frankenstein's dream of animating dead tissue. It is more the answer to Dr. Moreau's dream of combining various species into a new, unique creature. Nonetheless, as Lewis Thomas has observed, having man don the mantle of creator of life raises the fundamental questions that the Frankenstein myth exemplifies:

The recombinant DNA line of research is already upsetting . . . because it is disturbing in a fundamental way, to face the fact that the genetic machinery in control of the planet's life can be fooled around with so easily. We do not like the idea that anything so fixed and stable as a species line can be changed. The notion that genes can be taken out of one genome and inserted in another is unnerving.⁹¹

The Frankenstein myth resonated because of rDNA's ability to create new life forms that the creator could not control, and also because of the public's concern that scientists were doing this work for their own enjoyment, rather than society's betterment. As Mayor Vellucci put it, "I don't think these scientists are thinking about mankind at all. I think that they're getting the thrills and excitement and the passion to dig in and keep digging to see what the hell they can do."⁹² The mayor's statement

NETIC ENGINEERING WITH HUMAN BEINGS 14 (1982) (citation omitted) [hereinafter *SPLICING LIFE*].

⁹¹ *Id.* (citation omitted).

⁹² The U.S. Supreme Court confronted a similar argument when it was asked to decide whether microorganisms were patentable under the Patent Act. In rejecting a policy argument against patenting on the basis of unknown risks, the Court said:

To buttress his argument, the petitioner, with the support of *amicus*, points to grave risks that may be generated by research endeavors such as respondent's. The briefs present a gruesome parade of horrors. Scientists, among them Nobel laureates, are quoted suggesting that genetic research may pose a serious threat to the human race, or, at the very least, that the dangers are far too substantial to permit such research to proceed apace at this time. We are told that genetic research and related technological developments may spread pollution and disease, that it may result in a loss of genetic diversity, and that its practice may tend to depreciate the value of human life. These arguments are forcefully, even passionately, presented; they remind us that, at times, human ingenuity seems unable to control fully the forces it creates — that, with Hamlet, it is sometimes better "to bear those ills we have than fly to others that we know not of."

It is argued that this Court should weigh these potential hazards in considering whether respondent's invention is patentable subject matter under § 101. We disagree. The grant or denial of patents on micro-organisms is not likely to put an end to genetic research or to its attendant risks. The large amount of research that has already occurred when no researcher had sure knowledge that patent protection would be available suggests that legislative or judicial fiat as to patentability will not deter the scientific mind from probing into

encompasses not only the driving force behind Victor Frankenstein, but that behind Dr. Jekyll and Dr. Moreau as well. The President's Commission on Bioethics summarized the "Frankenstein factor" in rDNA research as follows: "The fear was that for researchers, creating a new life form — even a monster — would be a matter of curiosity; for the public, it would be an assault on traditional values."⁹³ As a result of its concern, the city of Cambridge developed regulations that called for laboratory inspections by a publicly-appointed committee.⁹⁴

C. Oversight Committees

Closely related to regulation is the establishment of oversight committees. The most prominent of these in the genetics research field has been the Recombinant DNA Advisory Committee (the RAC) and its subcommittee on genetic engineering. The RAC is a National Institute of Health

the unknown any more than Canute could command the tides. Whether respondent's claims are patentable may determine whether research efforts are accelerated by the hope of reward or slowed by want of incentives, but that is all.

What is more important is that we are without competence to entertain these arguments — either to brush them aside as fantasies generated by fear of the unknown, or to act on them. The choice we are urged to make is a matter of high policy for resolution within the legislative process after the kind of investigation, examination, and study that legislative bodies can provide and courts cannot. That process involves the balancing of competing values and interests, which in our democratic system is the business of elected representatives. Whatever their validity, the contentions now pressed on us should be addressed to the political branches of the Government, the Congress and the Executive, and not to the courts.

Diamond v. Chakrabarty, 447 U.S. 303, 316-17 (1980) (footnote omitted).

⁹³ *SPLICING LIFE*, *supra* note 90, at 16-17.

⁹⁴ The major flaw in Asilomar was the notion that science had the capacity to regulate itself without public involvement in the process. As Dorothy Nelkin noted:

[A] persistent theme throughout the dispute [over rDNA regulation] has been the conflict of interest implied by scientists regulating their own research. Metaphors have proliferated. To expect scientists to evaluate the risks in their own research is to ask 'incendiaries to form their own fire brigade,' or 'General Motors to regulate automobile safety,' or to ask, 'Would the tobacco industry limit the manufacture of cigarettes?' These questions explicitly challenge the assumption that scientists can transcend their narrow private interests and career concerns in making decisions which affect the public welfare. Scientists, it is argued, lack the moral authority and legitimacy to regulate themselves when their work could shape the future of society. Direct societal intervention is necessary to assure that the public interest is properly served.

Nelkin, *Threats and Promises: Negotiating the Control of Research*, 107 *DAEDALUS* 191, 197 (1978) (citation omitted).

committee that advises the Secretary of HHS on all matters relating to rDNA research, and reviews certain genetic experiments to approve them before they can be carried out. There are three specific areas over which the RAC has retained oversight, even in private facilities: (a) cloning toxin-producing genes; (b) introducing drug-resistance into an organism; and (c) deliberately releasing genetically engineered organisms into the environment.⁹⁵

Another type of oversight committee is one that studies an area and makes recommendations as to how that area should be regulated. Perhaps the most successful such entity to date has been the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, usually called simply "The President's Bioethics Commission" (1978-84). This Commission issued a number of very influential reports, including one on genetic engineering entitled *Splicing Life*. Among the Commission's recommendations was that the RAC broaden its areas of scrutiny "to include issues raised by the intended uses of the technique rather than solely the unintended exposure from laboratory experiments."⁹⁶ The Commission also sensibly suggested that the "next generation" RAC should be financially independent of federal funding agencies like NIH, in order to avoid any real or perceived conflict of interest. Although the RAC later did broaden its agenda to include prior review of all proposed research on genetic modifications of human beings, it remains part of NIH. As early as 1980 it was suggested that human trials should not begin until three conditions are met in animal trials: (1) the new gene should be put into target cells and remain there; (2) the new gene should be regulated appropriately; and (3) the presence of the new gene should not harm the cell.⁹⁷ When it is appropriate to begin human experiments with gene therapy remains controversial.

⁹⁵ J. AREEN, P. KING, S. GOLDBERG & A. CAPRON, *LAW, SCIENCE AND MEDICINE* 65 (1984).

⁹⁶ *SPLICING LIFE*, *supra* note 90, at 4.

⁹⁷ Anderson & Fletcher, *Gene Therapy in Human Beings: When is it Ethical to Begin?*, 303 *NEW ENG. J. MED.* 1293, 1295-96 (1980). See generally E. NICHOLS, *HUMAN GENE THERAPY* (1988).

D. Self-Regulation and Private Tort Suits

The RAC was heavily lobbied to transform its guidelines into voluntary "laboratory standards" in the early 1980s, but it refused. Most scientists prefer to police themselves, and not have nonscientists involved in monitoring or regulating their work. On the other hand, they are often horrified at the notion that they might be held personally responsible for the harm that their research might cause others. For example, the final formal speaker at the Asilomar conference, Professor Roger Dworkin, suggested that current law already imposes heavy obligations on scientists to be careful, and to have a laboratory workplace that is "free of hazard."⁹⁸ He got the scientists' immediate attention by suggesting that a multi-million dollar lawsuit "may sneak up on you"⁹⁹ if they're not careful. But he also made the equally important point that courts traditionally have looked to the industry to set its own standards, and almost always have relied upon industry standards to determine the relevant standard of care.¹⁰⁰

The fact is that in most areas, even those heavily regulated, the professionals themselves will have much control over the standards applied to their work. Under almost any standard, Victor Frankenstein and Dr. Moreau would be guilty of gross negligence and cruelty in abandoning their creations and in inflicting suffering upon them. Dr. Jekyll might properly argue that he was experimenting on himself,¹⁰¹ but he would still, of course, be criminally responsible for the murders committed by Mr. Hyde. The murderous experiments of the Nazi physicians during World War II led to the Doctors' Trial at Nuremberg, and to the articulation of the Nuremberg Code.¹⁰² It is now clear, although it should have been clear prior to 1947 as well, that experimentation on human beings without their consent (in exceptional circumstances proxy consent may suffice) is criminal activity, as well as a civil wrong against the person.¹⁰³

⁹⁸ M. ROGERS, BIOHAZARD 79-81 (1977).

⁹⁹ *Id.* at 79.

¹⁰⁰ *Id.* at 79-81. See also Dworkin, *Science, Society, and the Expert Town Meeting: Some Comments on Asilomar*, 51 S. CAL. L. REV. 1471 (1978).

¹⁰¹ See generally L. ALTMAN, WHO GOES FIRST? (1987).

¹⁰² TRIALS OF WAR CRIMINALS BEFORE THE NUREMBERG MILITARY TRIBUNALS UNDER CONTROL COUNCIL LAW NO. 10 (Vols. 1 & 2 1949).

¹⁰³ See generally Bassiouni, Baffes & Evrard, *An Appraisal of Human Experimentation in International Law and Practice: The Need for International Regulation of Human Experimentation*, 72 J. CRIM. L. & CRIMINOLOGY 1597 (1981); J. KATZ, EXPERIMENTATION WITH HUMAN BEINGS

Future lawsuits are likely to be of three kinds. The first may involve the accidental or purposeful release of a dangerous organism into the environment. This is the type of harm Mayor Vellucci worried about, and that could give rise to traditional tort suits alleging nuisance, trespass, battery, and negligent failure to contain the organism.¹⁰⁴ The second kind of suit may involve those who apply the new knowledge gained by the Genome Initiative to the clinical setting: cases involving wrongful birth (for failure to counsel about existing technology where the lack of knowledge results in a couple having a genetically handicapped child they would not otherwise have had); and cases involving wrongful life (suits by a child alleging that the child would have been better off not having been born, and would not have been born if the physician had properly counseled its parents or properly performed agreed upon screening tests).¹⁰⁵ The third type of lawsuit may be one for breach of confidentiality leading to a loss based on discrimination. For example, a physician may be sued for improperly disclosing a genetic diagnosis to an employer who then fires the employee on the basis of the genetic information.¹⁰⁶ As can be seen from this listing, tort suits will be most useful *after* genetic screening tests have been developed, and will likely have little impact on the test's development. In this regard it is at least of some interest that many physicians already consider the legal profession to be Frankenstein's monster incarnate, and consider malpractice attorneys every bit as destructive as the creatures on Dr. Moreau's island.¹⁰⁷

V. WHERE DO WE GO FROM HERE?

It seems reasonable to conclude from the various methods that have been employed to review genetic research and the clinical applications of

(1972); Symposium, *Ethical Aspects of Experimentation with Human Subjects*, 98 DAEDALUS 219 (1969).

¹⁰⁴ See *SPLICING LIFE*, *supra* note 90, at 14.

¹⁰⁵ See S. ELIAS & G. ANNAS, *supra* note 29, at 109-20 and sources cited therein.

¹⁰⁶ Cf. *Horne v. Patton*, 291 Ala. 701, 287 So. 2d 824 (1973).

¹⁰⁷ Dr. Vincent T. DeVita, former director of the National Cancer Institute, said, "Doctors are frightened to death of malpractice." Dr. William M. Hryniuk of the Ontario Cancer Foundation said, "Doctors tend to undertreat [in the U.S.] because they fear complications will lead to a lawsuit." Manual, *Professional Liability: A No-Fault Solution*, 322 NEW ENG. J. MED. 627 (1990). For representative statements, also see Annas, *Doctors, Lawyers and Wolves*, 29 JURIMETRICS J. 437, 438-39 (1989).

that research, that level one concerns will be dealt with by a combination of oversight committees, regulation, self-regulation, and private law suits. Level two concerns are not readily approached by private lawsuit, and so will likely require a combination of congressionally-mandated regulation, most likely based on suggestions by one or more advisory committees with broad public input. Although level three concerns are not subject to legal regulation, except where specific practices such as the purchase and sale of "high grade embryos" can be outlawed, this may be the area that has the most long term impact on us as a species, and therefore the one about which we need the most careful and creative thinking.

It is on level three that the cautionary tales with which this article opened focus. Mary Shelley's tale, for example, teaches us a lesson that we find hard to deal with seriously: as difficult as it is to create a monster, it is even more difficult to control it or to restore order after the creation has spawned chaos. In seeking to control our world, we may in fact lessen our control over it. Robert Oppenheimer unwittingly made this point in reference to the Manhattan Project when testifying before a congressional committee in 1945. He was testifying on the role of science in the development of the atomic bomb:

When you come right down to it the reason that we did this job is because it was an organic necessity. If you are a scientist you cannot stop such a thing. If you are a scientist, you believe that it is good to find out how the world works; that it is good to find out what the realities are; that it is good to turn over to mankind at large the greatest possible power to control the world¹⁰⁸

The striking thing in Oppenheimer's testimony is his emphasis on the notion that science is unstoppable, with the simultaneous insistence that its goal is *control* over nature. These irreconcilable concepts seem equally at the heart of the Human Genome Initiative. Of course, with the atomic bomb, control quickly became illusory. The bomb, which carries with it the threat of the total annihilation of mankind, has made the nation state ultimately unstable and put it at the mercy of every other nation with the bomb. Necessity has forced all nuclear powers to move, however slowly, toward a transnational community.¹⁰⁹

¹⁰⁸ R. RHODES, *THE MAKING OF THE ATOMIC BOMB* 761 (1986).

¹⁰⁹ The atomic bomb has, of course, transformed our entire existence to the point where, as

In view of the way scientists have thought about their pursuits and projects, it is informative to review the goals of the Human Genome Initiative set forth above in Part II with the list of the legal, ethical and social policy issues raised by the Initiative in Part III. It will be seen that there is almost no overlap. Scientists are working on an interesting scientific question to gain new knowledge and insight into what genes do, and what we can learn about man's origin and relationship to other species. If we take the scientists at face value, they have given no more thought to the potential social applications of genome mapping and sequencing than Victor Frankenstein had given to the consequences of creating his monster, or than Dr. Moreau had given to the consequences of his experiments in modifying life forms. Our own "brave new world" will not be ruled by scientists, any more than scientists decided whether to use the atomic bomb, or whether to send a man to the moon. Social policy will ultimately be set by elected politicians and their advisers. It is already past time to begin to involve the electorate in a national debate about the appropriate uses (and misuses) of the products of the Human Genome Initiative.

Martin Amis in his introduction to his five short stories on the atomic age has observed, "'Einstein's Monsters', by the way, refers to nuclear weapons but also to ourselves. We are Einstein's monsters, not fully human, not for now." M. AMIS, *EINSTEIN'S MONSTERS* i (1987). In the first story in this collection, "Bujak and the Strong Force or God's Dice," Bujak is described as having the following general worldview:

We live in a shameful shadowland. Quietly our idea of human life has changed, thinned out. We can't help but think less of it now. The human race has declassed itself. It does not live anymore; it just survives, like an animal. We endure the suicide's shame, the shame of the murderer, the shame of the victim. Death is all we have in common.

Id. at 48.

It is also noteworthy that following Hiroshima, Bertolt Brecht rewrote portions of his play, *Galileo*, to change its emphasis from one of scientific freedom from political authority to one that demanded:

[F]rom the scientists themselves a sense of social responsibility, a sense of identification with the destiny, not of other scientists only, but of people at large. The point was now to dissent from those who see scientific advance as 'an end in itself,' thus playing into the hands of those who happen to be in power, and to advance the alternate, utilitarian conception of science:

Galileo: . . . I take it that the intent of science is to ease human existence. If you give way to coercion, science can be crippled, and your new machines may simply suggest new drudgeries. Should you, then, in time, discover all there is to be discovered, your progress must become a progress away from the bulk of humanity. The gulf might even grow so wide that the sound of your cheering at some new achievement would be echoed by a universal howl of horror.

Bentley, *Introduction* to B. BRECHT, *GALILEO* 18 (1966). It is fair to say that the bomb overshadows not only all of science, but all human existence.

In this discussion, the focus should be on two central questions: what does it mean to be human, and how can human life on this planet be enhanced?¹¹⁰ To even begin to address these issues in the genome context, the public and the policymakers need to understand the Human Genome Initiative, and the cartographers of the human genome need to be able to recognize and deal with the real monsters lurking outside their laboratories.¹¹¹

¹¹⁰ The term usually used for enhancement is "happiness," but it is not a terrifically descriptive term and is overlayed with ambiguity. On the other hand, it was to foster "life, liberty and the pursuit of happiness" for the individual citizen that our government was in large part founded. But as Herbert J. Muller has rightly noted:

Once upon a time men believed, or at least were constantly told, that their main business on earth was the salvation of their immortal soul, through the service of God. In America today the popular word for the good life is "happiness." This seems to me a quite normal goal, but the question remains what people mean by the term. The American pursuit of happiness can often look like a compulsive, joyless effort to escape boredom, and in any case a people blessed with far more material advantages than any other society has ever enjoyed is not clearly the happiest people on earth. One plain reason is a paltry conception of the good life, or what I have called the highest standard of low living in all history. But this only forces the basic question. What, then, is the good life?

The whole history of thought and culture may be summed up as an endless disagreement over this question. . . . As Robert Kennedy observed (a few months before his assassination), the GNP takes into account "neither our wit nor our courage, neither our wisdom nor our learning, neither our compassion nor our duty to our country. . . . It measures everything, in short, except that which makes life worthwhile."

H. MULLER, *THE CHILDREN OF FRANKENSTEIN: A PRIMER ON MODERN TECHNOLOGY AND HUMAN VALUES* 5, 12 (1970). See generally L. WINNER, *THE WHALE AND THE REACTOR* (1986).

One leading commentator, psychiatrist Willard Gaylin, has thoughtfully suggested that we develop guidelines by which to determine the changes to encourage and the changes to discourage. His suggested set of human characteristics to encourage is instructive, and provides a useful basis on which to begin such a national discussion:

[A] life of imagination, esthetics, and hope; autonomy and freedom; a range of feeling that includes joy and pride, but *also* guilt and shame; a romantic sexuality; a joy in work (as distinguished from labor); a developed conscience; and that line of traits that leads from identification to friendship and love.

Gaylin, *Fooling with Mother Nature*, 20 HASTINGS CENTER REP., Jan./Feb. 1990, at 17, 21.

Gaylin's plea is that we focus on our goals, rather than on the "Frankenstein Factor" which he defines as being overly intimidated by high technology having the capacity to alter the nature of the human species. In this he is surely correct. He could have added that the focus is now on neither, and that it is past time to begin the national discussion on both. He also could have added that fear that produces constructive action is valuable, and a lack of fear, caused by ignorance or a denial of potential disaster, in itself produces disaster.

¹¹¹ Examples of past disasters abound, from environmental poisoning and degradation to urban chaos; from Agent Orange to Chernobyl; from the explosion of the space shuttle Challenger to thalidomide. We are now much more worried about the threat posed to the nation's health from our nuclear weapon plants themselves than we are about the threat of an attack from the Soviet Union

With both real and psychological walls crumbling around the world, the time may be at hand for meaningful international dialogue and cooperation on the Human Genome Initiative.¹¹² It may also be possible, although perhaps wishful thinking, to engage the world in a responsible debate about all of our futures, and to do so in a manner that strives to enhance the dignity of all human beings. Playwright, former political prisoner, and current president of Czechoslovakia, Vaclav Havel expressed it well in a 1984 speech on "Politics and Conscience":

To me, personally, the smokestack soiling the heavens is . . . the symbol of an age which seeks to transcend the boundaries of the natural world and its norms and to make it into merely a private concern, a matter of subjective preference and private feeling.

. . .

To be sure, this process of anonymization and depersonalization of power, and its reduction to a mere technology of rule and manipulation, has a thousand masks States grow ever more machine-like, men are transformed into statistical choruses of voters, producers, consumers, patients, tourists or soldiers. . . .

. . .

. . . The question is . . . whether we shall, by whatever means, succeed in reconstituting the natural world as the true terrain of politics, rehabilitating the personal experience of human beings as the initial measure of things, placing morality above politics and responsibility above our desires, in making human community meaningful, in returning content to human speaking, in reconstituting, as the focus of all social action, the autonomous, integral and dignified human I, responsible for ourself because we are bound to something higher As long . . . as our humanity remains defenceless, we will not be saved by any technical or organizational trick designed to produce better economic functioning, just as no filter on a factory smokestack will prevent the general dehumanization. To what pur-

that these plants were originally set up to prevent. See, e.g., Schneider, *Idaho Says No: The Nuclear Weapons Industry Has Worn Out its Welcome*, N.Y. TIMES MAGAZINE, Mar. 11, 1990, at 50, 58.

¹¹² See *The Rome Bioethics Summit*, 18 HASTINGS CENTER REP., Aug. 1988, Spec. Supp., at 11 (report on the fifth "bioethics summit meeting" which was devoted to the human genome). See also Watson & Cook-Deegan, *The Human Genome Project and International Health*, 263 JAMA 3322 (1990) (discussing international health implications of the Genome Project and international scientific efforts connected with the Project).

pose a system functions is, after all, more important than how it does so. Might it not function quite smoothly, after all, in the service of total destruction?¹¹³

Havel then adds, "I speak of this because . . . I cannot avoid the impression that many people in the West still understand little of what is actually at stake in our time . . . that Western culture is threatened far more by itself than by SS-20 rockets."¹¹⁴ He then goes on to elaborate that the task of all of us is to resist

at every step and everywhere, the irrational momentum of anonymous, impersonal and inhuman power — the power of ideologies, systems, *apparat*, bureaucracy, artificial languages and political slogans . . . whether it takes the form of consumption, advertising, repression, technology, or cliché We must not be ashamed that we are capable of love, friendship, solidarity, sympathy and tolerance, but just the opposite: we must set these fundamental dimensions of our humanity free from their 'private' exile and accept them as the only genuine starting point of meaningful human community.¹¹⁵

Havel's image of the smokestack is striking: the inanimate destroyer replaces the animate monster in industrial society. Governments grow more machine-like and, in consequence, treat their citizens as interchangeable parts of that machine. The machine-men become alienated even from themselves, and technology cannot save them from artificiality; their only savior will be their "natural" humanness and ability to distinguish good from evil.

Havel obviously did not have the Human Genome Initiative in mind when he delivered his 1984 speech, nor when he delivered a speech to a joint session of the United States Congress in February, 1990. Nonetheless, his 1984 words aptly summarize the challenge we face, and his 1990 words to the Congress properly insist that we all take personal responsibility for our own actions and the future of our world:

Without a global revolution in the sphere of human consciousness,

¹¹³ V. HAVEL, *LIVING IN TRUTH* 136, 138, 144, 149-50 (J. Vladislav ed. 1989).

¹¹⁴ *Id.* at 150, 152.

¹¹⁵ *Id.* at 153-54.

nothing will change for the better in the sphere of our being. . . .

We still don't know how to put morality ahead of politics, science and economy. We are still incapable of understanding that the only genuine backbone of all our actions, if they are to be moral, is responsibility — responsibility to something higher than my family, my country, my company, my success.¹¹⁶

Can the "new world" United States learn from the old? Can new science learn to take its social responsibilities seriously? Can we use our species consciousness to help us to confront not only the promise, but also the perils, of the new genetics? It will not happen easily in a country where new is still seen as better, and where the future is still seen as limitless. It is, after all, not Mary Shelley's but Gatsby's view of our future that prevails:

Gatsby believed in the green light, the orgiastic future that year by year recedes before us. It eluded us then, but that's no matter - tomorrow we will run faster, stretch our arms further. . . . And one fine morning -

So we beat on, boats against the current, borne back ceaselessly into the past.¹¹⁷

¹¹⁶ *Excerpts from Czech. Chief's Address to Congress*, N.Y. Times, Feb. 22, 1990, at A14, col.

4. In perhaps his most famous essay, "The Power of the Powerless," Havel wrote:

Technology — that child of modern science, which in turn is a child of modern metaphysics — is out of humanity's control, has ceased to serve us, has enslaved us and compelled us to participate in the preparation of our own destruction. And humanity can find no way out: we have no idea and no faith, and even less do we have a political conception to help us bring things back under human control.

V. HAVEL, *supra* note 113, at 114.

¹¹⁷ F. SCOTT FITZGERALD, *THE GREAT GATSBY* 182 (1925).