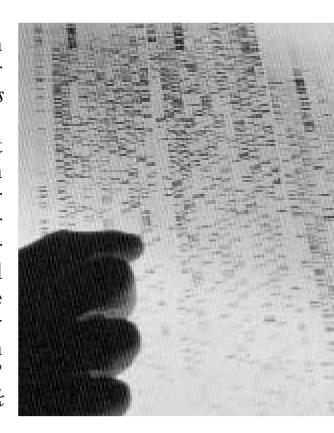
# Prometheus

"How dare you sport thus with life?"-Mary Shelley, *Frankenstein*, or *The New Prometheus* 

"Genetic power is far more potent than atomic power. And it will be in everyone's hands. It will be in kits for backyard gardeners. Experiments for schoolchildren. Cheap labs for terrorists and dictators. And that will force everyone to ask the same question—What should I do with my power?—which is the very question science cannot answer."

—Michael Crichton, Jurassic Park



or centuries, birth and death, the two great mysteries of human existence, were matters for God alone. Now science has intervened, with a variety of treatments and options for infertile couples, genetic manipulation and the possibility of human cloning edging over the horizon. Last year, the media exulted in the success of the "Human Genome Project" in mapping the whole of the common genetic endowment of man, and fantasized about the wonders to come as we master the mysteries of genetics.

Some of those "wonders" are already a reality, like the genetic alteration of crops and livestock to increase yield, size, resistance to plagues, etc., and the fast-advancing research into genetic therapeutic interventions on humans still unborn, or sick, maimed, or physically or mentally handicapped. There are already "transgenic" mice, which have inserted in their genome genes that are not usually found in their species, and recently we have been presented with "ANDi," a rhesus monkey with a jellyfish's gene for fluorescence! DNA profiling has become a source of additional information to be included in numerous databanks, such as those of national and domestic security forces, criminal forensics, institutions of education and employment, and medical, life and disability insurance companies. Other applications are



still in the realm of dreams or of unrealized hopes, such as the possibility of creating human clones as perpetual organ, limb and skin factories, and genetically engineered chimeras (part human, part animal). Still further possibilities include biological warfare and terrorism with products targeting specific genetic populations of crops, livestock and people.<sup>3</sup>

All the while, the clarification of guiding moral

principles has lagged behind technology.

This article does not pretend to be original. As a personal reflection on information culled from many sources, it is a brief exposition of those general moral principles, and a first, provisional application to recent developments in human genetics.<sup>4</sup> Its aim is not to be

<sup>1</sup> The United Kingdom has just legalized the cloning of human embryos for research purposes.

<sup>3</sup> Walker, Ten Points, 1-2.

The Human Genome Project began in the United States in 1990 under the sponsorship of the Department of Energy and the National Institutes of Health. It is—in its official description—"an international research effort to characterize the genomes of human and selected organisms through complete mapping and sequencing of their DNA, to develop technologies for genomic analysis, to examine the ethical, legal, and social implications of human genetics research, and to train scientists who will be able to utilize the tools and resources developed through the HGP to pursue biological studies that will improve human health."

an apologetic tool to bring straying geneticists back to the fold. This is not for lack of charity, but simply because it is impossible (and therefore useless) to argue with one who denies—as many scientists do—the absoluteness and immutability, and even the existence of basic principles of the natural and moral order. "Cum negante principio nequit disputari!" Rather, our goal is to offer to Catholics the fundamental moral guidelines regarding medical procedures that are now extraordinary and, in some cases, not even possible yet. As in the years to come many of these procedures will be first available and then common in medical practice, it is necessary to start pondering their moral implications now, to be able to deal with them when they become our problems of conscience.

Why is the clarification of moral principles necessary?

Because–even as Catholics–we live immersed in a world in which, during the past two centuries, a non-Christian understanding of nature, man and society has become generally accepted. Rejected at first, it has nevertheless pervaded common opinion, and the norms which entire generations had considered inviolable, the objective foundation of the moral order and the very existence of absolute moral laws, are now a matter of debate. Most of our contemporaries are guided by a new scale of values, secularized and utilitarian, which imply a new understanding of human nature.

God has become a mere hypothesis, to which one might subscribe or not, according to one's whims or needs. The religion of God Who became Man is today replaced by the religion of man who makes himself God. A man, who—in the words of Pope Paul VI<sup>6</sup>—is completely occupied with himself, a man who makes himself not only the center of everything that interests him, but who dares to proclaim himself the principle and ultimate reason of all reality. "The way of rational and immediate certainties has been set against that of God's commandments. Man thus returns to the dream of Greek thinkers, who, in the myth of Prometheus, claimed the right to direct their own destiny."

In the Greek legend, the pitiless gods had refused to grant fire to mankind, but Prometheus, knowing the benefits and the power to be drawn from fire, stole it and gave it to men. He was harshly punished for his transgression, but men also were punished for their boldness in appropriating what the gods had meant them not to have, and together with the benefits came indescribable sufferings...

Prometheus' myth has been reworked into more recent visions—such as Mary Shelley's *Frankenstein*. Frankenstein is, at the same time, the scientist and his creation, the famous monster that, out of unforgettable movies, haunted our childish imagination. Because of this, Frankenstein's name has become "a way to articulate our fears and doubts about science and technology." Consequently, when doubts about genetic technologies are voiced, some ridicule these

doubts as a so-called "Frankenstein syndrome," dismissing it as a sure sign of hysteria and ignorance.

Certainly, we do not accept the Frankenstein metaphor as literal truth, but neither can we deny that it has a point. These stories of old have a universal appeal because they express much-denied truths about human nature and morality, truths that not even a guilty conscience can ever wholly or successfully discard.

Frankenstein the scientist had a dream: to master the forces of nature and to disclose the secret of life, to alleviate human suffering and to annihilate that most universal of human fears, the pains and partings of death. In the pursuit of this dream he recognized no limits-what his insights and the consequent technology allowed him to do, he did, without any but technical restrictions. For him, the order of nature was not something fixed and unchangeable, but a new frontier waiting to be conquered. Moral boundaries were simply the impediments thrown in his way by small-minded, prejudiced, superstitious men, and he disregarded them, men and boundaries alike. Wasn't his intention good? Wasn't it the greatest evil he was trying to conquer? As today, his effort to break down biological barriers was clothed in the rhetoric of compassion and progress. Only too late, in the story, will he acknowledge and regret his rashness and ignorance...

A further lesson that can be learned from the Frankenstein story is that of

the uncontrollability and uncertainty of the consequences of human interferences with the natural order. Like the tale of the sorcerer's apprentice or the myth of the golem created from lifeless dust by the 16th century rabbi, Loew of Prague, the story of Dr. Frankenstein's monster serves as a reminder of the difficulty of restoring order if a creation intended to be helpful proves harmful instead. Indeed, each of these tales conveys a painful irony: in seeking to extend their control over the world, people may lessen it. The artifices they create to do their bidding may rebound destructively against them....

Prometheus or Frankenstein-these images are hard to dispel when we confront the progress of medical and biological sciences. Like Prometheus, this progress has put at our disposal more effective therapeutic resources and has given us new powers, but with unforeseeable consequences.

These techniques can enable man to take in hand his own destiny, but they also expose him to the temptation to go beyond the limits of a reasonable dominion over nature. They might constitute progress in the service of man, but they also involve serious risks. <sup>10</sup>

Like Frankenstein, a very real monster lurks in the shadows–if not necessarily in the produce of the laboratories, at least in the divisive ethical controversy provoked by the new knowledge, and in the depths of human and scientific pride.

### A MODERN VISION

#### THE GENES-R-US?

It is a fact that, since the 18th century, fueled by the "scientific revolution," a materialistic worldview has rejected the existence of any spiritual or immaterial principle in man. Life has been reduced—in the words of Lavoisier<sup>11</sup>—to a complex of chemical reactions, and the very being of man himself to the material components of his body. As the human genome is the whole of the heritable genetic material that seems to direct the development of the human organism, <sup>12</sup> scientists have contended that not only the physical, but also the psychological and social characteristics of men are causally determined by the human genome, and are, therefore, unavoidable.

This has become, unfortunately, a widespread popular view.

Daily we are told-by Barbara Walters, by newspaper journalists, and above all, by proponents of the Human Genome Project—that it is our genes that make us "what we are," that make some of us musical geniuses, Olympic athletes, or theoretical physicists, and others alcoholics, manic-depressives, schizophrenics—even homeless. The Office of Technology Assessment concludes that "one of the strongest arguments for supporting human genome projects is that they will provide knowledge about the determinants of the human condition"; that, especially, the Human Genome Project promises to illuminate the determinants of human disease, even of those diseases "that are at the root of many current societal problems." <sup>13</sup>

In this fatalistic proposition, the modern myth of "genetic determinism" asserts that the DNA defines who we are and who we can be, that it is the ultimate explanation of the human being, that we are immutably destined to act as our genetic program determines us to act. The ethical conclusion is distressing—a kind of natural innocence is regained, because we are no more responsible for what we do...<sup>14</sup> This idea has obvious appeal to many of our contemporaries, the creators of the modern "culture of victimhood," <sup>15</sup> always eager to find any excuse to minimize their personal responsibility, and to shift effectively and conveniently the burden of personal guilt onto somebody else—in this case, their parents, who have given them their genetic inheritance.

#### A Brave New World

This determinism, when compounded with the promises heralded by genetic technology, opens up frightening vistas into the future, especially when applied to human beings. Why frightening? Because we live in a post-Christian world. That is, in a world that—in Chesterton's words—has rejected the Christian ideal, not because it has been tried and found wanting;

but simply because it has been found difficult and discarded. The Christian–real–view of man and of nature has consequently faded from our contemporaries' minds.

In the past, in a world still shaped by Christianity, the human being was considered the summit of creation, created in the image and likeness of God, with all the rights and duties that arise from such dignity. Today, God and spiritual realities are denied or pushed into the background. A reductionist view of man has taken over, centered and overwhelmingly concerned with the physical part of our being. The human body has come to be seen almost as no more than a machine.

"In fact, we are so imbued with the doctrine of mechanism that we often perceive our body's organs, substances, sub-parts, genes, and cells as indistinguishable from the other mechanical and technological products in the marketplace." We see "courts legally defining the body as a 'factory', and allowing for the paid 'manufacture' of a baby by a surrogate mother," and "the advances in the machinelike manufacturing of life through cloning." We observe "governments and corporations patenting animals and human body parts just like any other 'manufactures'...and animals being created as 'bioreactors' for valuable human genes, and the bodies of the dead used as 'storage' for valuable organs...." 16

Ours is also (as another author puts it)

a society of increasing complexity, in which the collecting, exchanging, re-arranging and discarding of information is proliferating at an unparalleled speed, and in which personal and institutional success is measured in terms of the ability to process increasingly complex amounts of information.  $^{\text{T}}$ 

Nature has been cast, then, in the image of the computer, and consequently, in tune with this new vision, the front-line science, genetics, is conceived as the programming of living beings. Living beings are

- This article is also the by-product of the lectures given to the SSPX Priests in their annual Session of Studies, held at St. Thomas Aquinas Seminary, on Feb. 12-16, 2001.
- 5 That is, "It is impossible to argue with somebody who denies the principle!"
- <sup>6</sup> Paul VI, Discourse for the closing of the Second Vatican Council, December 7, 1965.
- Joblin, Euthanasia, 6.
- <sup>8</sup> See Rollin, *The Frankenstein Syndrome*.
- 9 Presidential Commission, Splicing Life, 1983. in: Shannon: Bioethics, 403-404
- <sup>10</sup> Congregation for the Doctrine of the Faith, *Donum Vitae*.
- Antoine-Laurent Lavoisier (1743-1794), French scientist, regarded as the founder of modern chemistry.
- We refer the readers to the appendix to this article, where the basic technical aspects of human genetics are exposed in a very simplified manner.
- 13 Keller, Nature, 356.
- <sup>14</sup> Peters, *Playing God*, 6-7.
- 15 See Charles Sykes. A Nation of Victims. The Decay of the American Character. New York: St. Martin's Press, 1992.
- <sup>16</sup> Kimbrell, *Human*, 234.
- 17 Rifkin, Biotech, 212.

perceived, not in their concrete reality, but as bundles of genetic information. The geneticist in *Jurassic Park*, for example, does not see his cloned dinosaurs as living beings, but as scientific quizzes to be mastered and solved–after which he nimbly extricates himself from any further responsibility for the beings he has brought to life. In the end, of course, there is a price to be paid.

The mystery of life having thus been reduced to a code to be deciphered, it appears now that it can be manipulated with no more trouble than the "source code" of our computer programs. In logical continuity with this view, the more frequently raised "ethical" issues seem limited to questions of privacy and fairness in the use of genetic information, patenting and monopolies, *etc.*<sup>18</sup>–just the same issues that worry us regarding our computers!

We arrive thus at the final corollary of the myth of genetic determinism, its "promethean" proposition. That is, the assurance that the inexorable progress of knowledge will lead us to the development of technologies that will give us mastery over what nature has bequeathed us, we will be free from the vagaries of "evolution" and able to control our own destiny—compounded with the blind trust that we do know how to use wisely such power. <sup>19</sup>

In this post-Christian view, of course, there is no question of any sacredness either of life or of man, nor are there any pre-determined boundaries, divine or natural, to be respected.<sup>20</sup>

## CATHOLIC PRINCIPLES

So much nonsense as it is today uttered arises from ignorance—the ignorance of the true nature of man, and the denial of the existence of a spiritual soul and of an unchangeable natural and moral order.

Scientists, as a breed, do not welcome philosophical reflection–Richard Feynman is supposed to have described the philosophy of science as being as useful to scientists as ornithology is to birds. <sup>21</sup> That is, of course, part of the problem. In spite of them, though, the philosophical foundations must be laid down before we venture into the uncharted waters of the possible uses of the powers offered to mankind by modern genetics. We let our attention be grabbed by headlines, that is, we try to find answers to immediate problems without stepping back and considering the questions and arguments the answers depend on. These questions are as old as philosophy itself–What is life? What is man? What gives a man his individuality? What mastery do we have upon ourselves?

#### LIFE

Rather than start with an abstract definition of "life," let us consider firstly those beings that, in the

common estimation of men, can be said to be "living."

The living being is that which has certain characteristic physical operations: organization, nutrition, reproduction, conservation, and growth. Organization consists in the differentiation of parts and the coordination of functions: a living body is composed by different organs, performing different functions, which contribute to the good of the whole. Nutrition is the changing of a substance into the very substance of the living being. Reproduction is a division of cells that ends in the production of a new organism similar to the original. The two last characteristics, conservation and evolution, go together: they refer, not to evolutionism, but to the growth and aging of the individual, remaining always the same individual in spite of those changes. From a scientific point of view, nothing else can be added, because science is restricted to the observable phenomena.<sup>22</sup>

The metaphysical notion of life starts from this common experience of the living being as characterized by spontaneous movement. Movement does not mean simply to be able to go from one place to another. It must be understood in a much wider, metaphysical sense as any kind of change, that is, of passage from potency to act.

Life is, then, a capacity for immanent activity.<sup>23</sup> This capacity and its actual exercise are entirely due to the presence of the soul, substantially united to the body. The material bulk of a body cannot account for its life.

The structure of a body as an organism does not account for life-activity, but this very structure has to be built up according to a set plan before it is operative, and this building is due to an indwelling substantial principle which is not that thing which is built; even after building, the organic structure does not explain its permanence or its actual functioning, for in itself, it is only a structure suited for its functioning, and a substantial activating principle is still required to explain the fact that it does actually exercise vital operations. There must be, in a word, a first informing and substantial principle which makes the body alive; which determines the body as plant, animal, or man; which holds the body in its organic and functioning unity. This substantial principle we call the soul. (...) The soul is the substantial principle of life which constitutes the organism and is substantially fused with the organism in the unity of a living body, and it is the root of all operations of the living body, even those activities which it uses as instruments and which are in themselves mechanical or physico-chemical.24

Regarding its origin, this activity is spontaneous, that is, it proceeds from within–a living being has within itself the principle of its activity, the soul. That activity may be influenced by a great number of external factors, conditions and causes–but these factors would not have any effect if the being were not already "living," transforming by its own initiative and power what it receives from without.<sup>25</sup> Regarding its terminus, this vital activity is immanent, that is, it remains within the living being, he is the term of his own activity. Living beings act for their own

advantage, seeking both to sustain their own being and to acquire its full development.

Life in living bodies manifests a scale or gradation, according to the degree of immanence of the activity, from the crude interiority of vegetative life to the true immanence to be found at the level of human intelligence. It arrives at its highest degree in the perfect possession of self in God.<sup>26</sup>

#### THE NATURE OF MAN

Man, as a living being, is composed of soul and body. He is not a body alone, or a separated spirit, but a composite of rational soul and material body.

The soul is the principle of the substantial existence of the body, in such a manner that the two elements, biological corporeality and spiritual soul, do not constitute two beings but one. This soul does not exist before the body, but it is created directly by God at the same instant as the body is formed by the fusion of the human egg and sperm.

In philosophical terms, we say that the soul is the form of the body, that is, the principle of being and action of the body. The soul makes the body exist as a living substance, gives it its organization and unity, and maintains both as long as it remains united to the body. The soul is also the first intrinsic principle of the activity of man, that is, it is the principle of all the vital acts: nutrition, movement, sensibility, thought...<sup>27</sup>

Two consequences of this doctrine have to be made clear. First, the soul is capable of subsisting by itself—it is capable of existence by itself without the body. But it is not a complete man, it is only part of a human being—it is created to inform a body, it has an essential relationship to it.<sup>28</sup>

The second consequence is much more significant for the subject of this article. If the soul is the form of the body, nevertheless it receives from the body its individuality. When a being is composed of matter and form, as man is, these two elements have a complementary function: the form (soul) specifies and actualizes the matter (body), but the matter individuates the form. Let us explain further. All men have the same "humanity," that is, their souls are all of the same nature, identical in their essence. But souls are diversified because the bodies that they inform are necessarily different. A man's body plays, then, an essential role in constituting his individuality. In simpler words, the soul makes a man to be a man and makes his body to exist and to live-but the body is what makes him a different being, separate from all others.<sup>29</sup>

#### GENOME AND INDIVIDUALITY

What is the human genome? It is the germ and program of the human body. Then, does this mean that my genome makes me to be myself? No. The fact that the genetic structure is exactly the same, to the

last trait, in the case of identical twins (developed from the same egg) makes it clear that the genome, all by itself, does not explain the uniqueness and individuality of the person.

Man is "this man" only by the union of the soul with the body. The soul is forever after, in its individual nature, what it has become by its infusion in this body. The person remains unaltered, whatever may happen to the body. The human genome, no matter how awe-inspiring it is, can never be revered as if it were the cause and creator of the human person.

The "program" contained in the human genome is primarily a meaningful plan aimed at a divinely preordained goal. Secondarily, however, because this genetic program is not only stored in the DNA, but also operates and is implemented via the living structure of the organism in which this program is saved and operative, it is open to the lack of due perfection—the "evil"—that may occur in natural processes. This makes possible deviations and all kinds of genetically pre-ordained tendencies towards malformation and diseases. <sup>30</sup>

In conclusion, then, even

if a theory of heredity, based on the knowledge of cellular structure and the laws of hereditary transmission, is able to say why a man has certain hereditary characteristics, it is not in a position to explain the whole life of man.  $^{31}$ 

#### Mans Dominion Over His Body

Let us reiterate here, very briefly, the Catholic doctrine on the dominion that man has over his life and body.  $^{32}$ 

## MAN HAS ONLY THE USE NOT THE ABSOLUTE PROPERTY OF HIS BODY

Man, in truth, is not the owner of his body, nor its absolute lord, but only its user. A whole series of principles and norms derives from this fact, governing the use of the body with its members and organs, and the right to dispose of them.<sup>33</sup>

Man is the steward of God, from Whom he has received his body and soul, to administer them in a

- <sup>18</sup> See NIH, Human Genome Project.
- 19 Peters, Playing God, 7.
- 20 Rifkin, Biotech, 214.
- <sup>21</sup> The noted physicist is quoted in Penman, What Are Genes?, 67.
- <sup>22</sup> Verneaux, *Philosophie*, 14.
- <sup>23</sup> Glenn, Introduction, 295.
- <sup>24</sup> Glenn, Introduction, 297-298.
- <sup>25</sup> Verneaux, *Philosophie*, 14; Gardeil, *Psychology*, 18-19.
- <sup>26</sup> Verneaux, *Philosophie*, 14-15; Gardeil, *Psychology*, 19-20.
- <sup>27</sup> See Verneaux, *Philosophie*, 178-186.
- <sup>28</sup> Glenn, Introduction, 310; Verneaux, Philosophie, 182.
- <sup>29</sup> Verneaux, *Philosophie*, 182-184.
- Seifert, Respect, 364.
- Pius XII, Allocution (1953), n.458.

manner convenient to the attainment of the end for which he has been created, the vision and love of God. A steward does not have absolute dominion over the goods so entrusted to him, but is bound to administer them according to the will of the owner.

It is commonly understood, though, that the administrator of any property has the power to manage it, by performing the actions that are necessary for preserving that property in existence, and for its well-being. In fact, it is the intention and expectation of the rightful owner that he will do so.

The only limits to this power of disposal are established by the natural finality of the faculties and forces of his human nature:

In forming man, God regulated each of his functions, assigning them to the various organs....At the same time, God fixed, prescribed and limited the use of each organ. He cannot therefore allow man now to arrange his life and the functions of his organs according to his own taste, and in a manner contrary to the intrinsic and immanent function assigned them.<sup>34</sup>

MAN HAS DIRECT POWER OVER THE MEMBERS AND ORGANS OF HIS BODY TO PRESERVE HIS OWN EXISTENCE AND HEALTH.

The bodily members and organs of man are constitutive of his physical being. These physical parts are subordinated to the good of the whole. In this manner, then, man can dispose of (that is, treat, change, remove, *etc.*) those physical parts whose presence and activity endangers the life of the whole, that is, his own life. Man

cannot freely dispose of himself as he pleases. Even the motive for which he acts is not by itself either sufficient or determining. [Man] is bound by the immanent purposes fixed by nature. He possesses the right to use, limited by natural finality, the faculties and powers of his human nature. Because he is the beneficiary, and not the proprietor, he does not possess unlimited power to allow acts of destruction or of mutilation of anatomic or functional character. But, in virtue of the principle of totality, of his right to employ the services of the organism as a whole, he can deliver individual parts to destruction or mutilation when and to the extent that is necessary for the good of his being as a whole, to ensure its existence or to avoid—and naturally to repair—grave and lasting damage which could otherwise be neither avoided nor repaired. 35

### GENETIC ENGINEERING

The expression "genetic engineering" embraces many concepts, including gene manipulation, gene cloning, recombinant DNA technology, gene therapy and genetic modification.<sup>36</sup> In simple words, "genetic engineering" refers to the technology that allows one to identify genes, to isolate them from the chromosomes, and to splice them into other

chromosomes of beings of the same or different species.

The moral exploration—from a Catholic perspective—of all the possibilities opened up by genetic engineering would require a treatise well beyond the capacities of this author and the patience of the readers. For that reason, we will restrict ourselves, in this article, to the one question of the *therapeutic manipulation of the human genome*.

Pope John Paul II has pointed out that—when used in reference to human beings—the terms "genetic engineering" or "genetic manipulation"

[remain] ambiguous and should constitute an object of true moral discernment, for [they] cover, on the one hand, adventuresome endeavors aimed at promoting I know not what kind of superman and, on the other hand, desirable and salutary interventions aimed at the correction of anomalies such as certain hereditary illnesses....<sup>37</sup>

# W ITHIN LIMITS, CERTAIN TYPES OF GENETIC ENGINEERING ARE MORALLY PERMISSIBLE

As we have seen, the human genome is a part of the human body, certainly fundamental, but not the only constitutive part of the human being. As a part of the whole, according to the principle of totality, it is subordinated to the good of the whole—that is, to the physical life and health of man, and, in the last resort, to his spiritual welfare.

While man is not the proprietor of his body to do with it as he pleases, he is nevertheless entrusted by God with its care and preservation. It is man's duty in justice to assure the continuation in existence of his body, and "to avoid and repair any lasting damage" that could threaten his life and health.

The limitations are thus clearly established: the intervention in the genome has to be therapeutic in intent, and it must not thwart the natural, immanent finality of man's being. That is, these interventions must restore and assure, not impede, the natural functions of his organs, and leave unimpaired the use of man's intelligence and free will, which are the means to attain the ultimate finality of his existence, the vision and love of God.

The body, with its aptitudes and its organs, is only the instrument, while the soul is the artist that plays on that instrument. Again, the ability of the artist can compensate for many defects of the instrument; but one plays better and more easily on an instrument that is perfect; and when its quality falls below a certain level, it becomes absolutely impossible to use....Genetics teaches us to understand the instrument better in its structure and variations, and to make it play better.<sup>38</sup>

Let us see, then, what are the moral boundaries for the genetic engineering of man. We will proceed in the order of how soon these technologies are becoming available—that is, of how soon they are likely to become *our* problems of conscience.

Genetic testing is already widely used, and will become more so as the genome is completely sequenced and correlations are established with particular diseases. Somatic therapy is being heavily researched today, and there are already some concrete applications, although still highly experimental and expensive. Germ-line therapy and genetic enhancement are still remote possibilities, but research is also moving in this direction.

Let us see, then, in order, three kinds of genetic engineering: *gene testing*, *gene therapy*, and *gene enhancement*.

#### GENETIC TESTING

#### GENERAL NOTIONS

A genetic disorder is a consequence of defects in single genes or in whole chromosomes, parts of which may be lost, duplicated, or misplaced. It may also be due to the interaction of multiple genes with external factors in fetal or early post-natal development.

Ongoing research has permitted scientists to identify the genetic basis of many diseases. At the same time, it has allowed the development of tests to detect the presence of the genes associated with those diseases, or predisposing those who inherit the gene to disease.<sup>39</sup> The overall aim of genetic testing is to diagnose the disease early enough to initiate treatments that will prevent permanent and irreversible damage, even death.

#### Forms of General Testing:

Pre-symptomatic testing is that which is performed on an apparently healthy individual—who is suspected to be at risk for some genetic disease—to ascertain whether he is really suffering from the genetic defect that will trigger, later in life, that disease. Carrier testing is performed, on the other hand, to detect whether healthy individuals have genetic defects that, while not affecting them, will pose a threat to the health of their future progeny.

#### **Pre-Symptomatic Testing:**

#### PRENATAL TESTING

Here the test is performed to determine whether a particular genetic disease is present in the offspring before birth. It is suggested that the information may be used by the parents to plan ahead for raising a child with disabilities. Unfortunately, it usually provides a motive to abort, or, if the parents are using artificial reproductive technologies, to discard gametes or zygotes with the disorder.<sup>40</sup>

The habitual techniques for prenatal testing are amniocentesis<sup>41</sup> and chorionic villi sampling. <sup>42</sup> Both methods imply serious risks for the child. Amniocentesis has a rate of fetal loss of 1 in 200. Chorionic villi sampling poses greater risks, such as limb reduction, malformation and spontaneous abortion, results of its being performed earlier in the pregnancy, that is, at an earlier stage of development.

#### POST-NATAL TESTING

Testing of newborn infants is commonly done to detect conditions such as hypothyroidism and sickle cell anemia that would result in serious harm to the child, but for which early treatment can be initiated to prevent death, mental retardation or permanent disability.<sup>43</sup> The usual technique for testing is through blood samples. As this procedure may give some false-positive results, it is recommended—if the result is positive—to follow it up with more sophisticated testing.

Some genetic diseases have no early signs, or only manifest themselves later in life. The testing is valuable to identify diseases that are dependent on only one defective gene–such as Huntington's chorea–before their onset later in a person's life. Diseases such as breast cancer, colon cancer, and Alzheimer's, on the other hand, require the presence and interaction of multiple defective genes, or of particular environmental conditions in combination with the genetic trait; a positive test, therefore, does not necessarily imply that the person will develop the disease; it only indicates an increased predisposition for the specific disease.<sup>44</sup>

- 32 See Iscara, Immorality.
- <sup>33</sup> Pius XII (1944), in: Solesmes, *Human Body*, 54 (n.32).
- <sup>34</sup> Pius XII (1944), in: Solesmes, *Human Body*, 54 (n.32).
- 35 Pius XII (1952), in: Solesmes, Human Body, 198-199 (n.359)—emphasis added.
- <sup>36</sup> Jenkins, Genetics, 128.
- John Paul II (1983), Address. Initially, researchers tended to call genetic manipulation "genetic therapy," for its public relations value, that is, to suggest that all these intended manipulations would be beneficial for man.
- <sup>38</sup> Pius XII (1953), n.461.
- <sup>39</sup> Usually, the term "testing" is reserved for the analysis of the genetic make-up of one individual, and "screening" is used to refer to widespread testing throughout a clearly delimited population, to determine the common genetic traits.
- 40 Center for Bioethics, New Frontiers, 6-7.
- In amniocentesis, amniotic fluid is withdrawn from the uterus by a needle inserted through a woman's abdomen, using ultrasound to circumnavigate the fetus and placenta. Spinal cord defects and genetic abnormalities such as Down syndrome, Tay-Sachs disease and cystic fibrosis can be screened for by amniocentesis. It can also be used to determine the sex of the fetus. Not all birth defects, however, can be detected by this procedure. (Encyclopedia Britannica, "Amniocentesis").
- The technique of retrieving a sample of the small projections (villi) that increase the surface of the outer embryonic membrane (chorion) within the uterus is similar to amniocentesis but can be carried out much earlier in pregnancy, between the 8th and 12th week of gestation. (Encyclopedia Britannica, "Pregnancy: Chorionic Villi Sampling").
- <sup>43</sup> Center for Bioethics, New Frontiers, 7.

#### CARRIER TESTING

Carriers are persons with one normal and one abnormal copy of a gene. Since one normal gene is present, carriers do not exhibit clinical symptoms. The purpose of this kind of test is to offer to prospective parents information about risks to their offspring. The results of the test, though, may be misleading. In the case of cystic fibrosis, there are almost 700 identified mutations of the gene, but not all of them actually result in the disease; the usual test, for 70 of the most common mutations, appears to fail in detecting 1 in 10 cases.<sup>45</sup>

#### MORALASSESSMENT

To discern the moral permissibility of any medical procedure, we must first remember that the complete morality of an act arises from the combined consideration of (1) its **object**, that is, the end to which the act tends by itself and which is immediately achieved; (2) the **circumstances** that surround the concrete performance of such an action; and (3) the **intention** of the agent who performs it. If those three elements are morally good, the action is good. If any of them is morally evil, the action is evil, whatever the goodness of the other elements may be.

## GENETICS MADE EA

he human genome is the whole of the heritable genetic material that directs the development of the human organism. Authors of popular works on science usually liken the genome to a "blueprint" that directs the construction of our physical being. But, personally, I find more congenial and understandable the description of the genome as a book—written in a particular language, subdivided into sections, chapters, paragraphs, sentences, words, each composed by multiple letters—all of which mean something and transmit this meaning to the reader.

This "book" has 23 chapters (chromosomes), and each chapter contains several thousand stories (genes). Each story is made up of paragraphs (exons), which are interrupted by "advertisements" (introns). Each paragraph is in turn made up of words (codons). There are one billion words in the book. Each of the three-letter words is written using only four letters (bases): A, C, G, and T, which stand for Adenine, Cytosine, Guanine and Thymine. Simple, isn't it? No? Well, let us see.

#### GENETIC HEREDITY

Every man starts life as just a single cell, formed by the fusion of his parents' germ-cells (ovum, i.e., the unfertilized egg, and sperm). All the information needed to build up the adult body is contained inside that initial cell, in its nucleus, where there are thousands of genes<sup>2</sup> on 23 pairs of threadlike bodies called chromosomes.

Differences among individuals conceived from the same parents arise from the particularities of the process of reproduction. The two gametes (the germ-cells, that is, sperm and ovum) are produced in the gonads (ovaries in females and testes in males), by a process called meiosis. Because of the assortment and separation of chromosomes during this process, each one of us produces gametes containing diverse combinations of the chromosomes we inherited from our parents. During meiosis, another process, called recombination, or "crossing over," produces individual chromosomes that combine genes inherited from the two parents. A human ovum, representing one of approximately 8 million possible chromosome combinations, will be fertilized by a single sperm cell, which represents one of 8 million different possibilities. In this manner, it results

that a child's chromosome set is unique to him.3

When the child is conceived, the fusion of the gametes gives him a complete set of 46 chromosomes (one set of 23 from the father's sperm and the other 23 from the mother's ovum). The two chromosomes of each pair carry genes controlling the same inherited trait (for example, if a gene of eye color is situated in a particular place in a chromosome, its homologue will also have a gene specifying eye color in that place). If the two genes are identical, the person will show the trait that they specify, say, blue eyes. However, if the genes are different, one will be dominant and the other recessive—that is, the dominant will express the trait it commands, overriding the trait expressed by its pair, and the recessive will remain hidden in the background, not expressed.

Every one of the 100 trillion cells that compose the human body<sup>6</sup> contains an exact copy of the individual's *unique* sequence of genes in 23 pairs of chromosomes put together at the moment of conception.

#### THE LANGUAGE OF GENES

But, what is a "gene"? A gene is, in simple words, a set of instructions that tells a cell exactly how to make a certain kind of protein. Every human body is built and run with fewer than 100,000 kinds of protein molecules.

Virtually every process and product in living cells depends on proteins. They do everything from activating essential chemical reactions, to carrying messages between cells, to fighting infections, to making cell m embranes, tendons, muscles, blood, bone, and other structural materials.... Despite their many different functions, all protein molecules are constructed in the same basic way. They are long, folded chains of smaller molecules called amino acids. 7

Each "word" in the sequence tells the cell what raw materials to take and the order in which to produce the different amino acids which, in turn, make up the proteins. There are 20 different kinds of amino acids, the same in all living organisms, from protozoa to plants, animals and humans. Most of the common proteins are formed by more than 100 amino acids. "The numbers, types, and arrangement of amino acids in a protein molecule determine its structure, and its structure determines

#### On Pre-Natal Testing:

The Encyclopedia Britannica states approvingly that "screening of the susceptible population for Tay-Sachs has significantly lowered the number of newborns affected by this lethal disease in the United States."  $^{46}$ Translated, this terse "newspeak" means that, following the genetic tests, the prospective parents have chosen either to use contraceptive methods or to abort.

Gilbert Meilaender cuts ruthlessly through the euphemisms:

The day may come when we can treat and cure prenatally or postnatally many genetic diseases; however, for the moment, we can diagnose prenatally far more that we can treat. In the meantime, therefore, we screen and abort. For now that is essentially the only "treatment" for illness diagnosed prenatally. We know more and more about the child in utero; hence, people (...) seek and use such knowledge in order to select the babies they desire and abort those they do not want.47

- Center for Bioethics, New Frontiers, 8-9.
- <sup>45</sup> Center for Bioethics, New Frontiers, 4-5.
- <sup>46</sup> Encyclopedia Britannica, "Genetic Screening."

## SY

the job it will do in a living organism. The shape of some proteins is very sensitive to the arrangement of particular amino acids, and a change in the identity of only one amino acid can cause very subtle, or very profound, effects-like a misspelled word altering the meaning of a sentence."9

#### THE DOUBLE HELIX

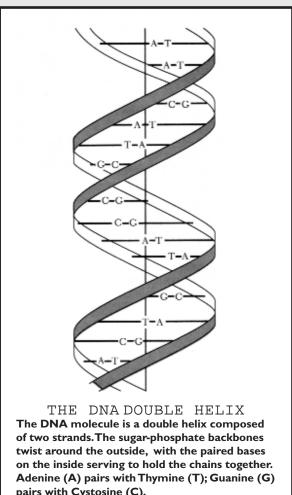
Each chromosome is one pair of long DNA (deoxyribonucleic acid) molecules, built up by nucleotides, repeating subunits of three linked molecules—base, sugar and phosphate.

The usual state of DNA is a "double helix," the original strand and a complementary pair intertwined, like a twisted rope ladder (the side "ropes" of sugar and phosphate) with wooden rungs (the complementarily bonded pairs of bases). 10

The bases are complementary, that is, A on one chain bonds only to T on the other (thus forming an A-T ladder rung); similarly, C on one chain bonds only to G on the other. If the bonds between the bases are broken, the two chains unwind, and free nucleotides within the cell attach themselves to the exposed bases of the now-separated chains. These free nucleotides line up along each chain according to the base-pairing rule (A bonds to T, C bonds to G). This process results in the creation of two identical DNA molecules from one original and is the method by which hereditary information is passed from one generation of cells to the next.

The human genome is composed of about 3 billion base pairs and possibly contains 50,000 genes. The genes take up only about 5 to 10 percent of the DNA; some of the remaining DNA, which does not code for proteins, may regulate whether or not proteins are made, but the function of most of it is still uncertain.

What is known is that the DNA sequence also includes groups of genes (regulator genes) that promote or inhibit the activity of the other, protein-producing genes (structural genes). There is also a third type of genes (operator genes), which control the activity of either one or multiple regulator genes, together with their structural genes. When genetic engineers transfer genes from one organism to another, they must include all these "switches" that control the genes, as well as the genes themselves.



## pairs with Cystosine (C).

#### GENE EXPRESSION

All the cells in a human body contain identical copies of the genome (the complete sequence of genes), but only relatively few (1,000-5,000) are at work-"expressed"-in every cell at any one time. The others are inactive ("repressed" or "turned off") much or even all of the time.

Most of the active structural genes perform "housekeeping" chores, carrying out the metabolic reactions common to all cells, but a few (100) carry codes for proteins needed only

#### MOTIVE

Thus knowledge, or information, although in itself morally neutral, cannot be separated from the *motive* for seeking it. From that motive, the genetic test will receive its first moral qualification.

If the knowledge is sought to initiate treatment that may reduce the consequences of the defect, and insofar as excessive anxiety and despair are avoided, the genetic screening might be morally good.

It is very easy to deceive ourselves by asserting that the knowledge is sought to prepare better for the raising of a child with disabilities. Perhaps it is so, but it is imprudent to pursue the acquisition of this information only for this motive—it will taint our gift of life, creating regrets, a reluctance to accept the child even before he is born.

On the other hand, if the test is performed with the intention of aborting the child if he presents any of the tested for genetic defects, the testing is morally evil–a sin. Nothing justifies direct abortion.

Every human being, even a child in the mother's womb, has a right to life directly from God and not from the parents or from any human society or authority. Hence there is no man, no human authority, no science, no medical, eugenic, social, economic or moral "indication" that can offer or produce a valid juridical title to a direct deliberate disposal of an innocent human life; that is to say, a disposal that aims at its destruction, whether as an end or as a means to another end, which is, perhaps, in no way unlawful in itself.<sup>48</sup>

#### CIRCUMSTANCES

To the basic moral qualification given by the motive, there has to be added the moral evaluation of the concrete *circumstances* of the testing. As we have

in that type of cell. For example, while all the cells of the body have the genetic information to make insulin, <sup>11</sup> this protein is manufactured only in the pancreas, to be carried by the blood-stream to all the other cells where it is needed.

#### GENETIC VARIATION

As we have seen, genetic variation among individuals conceived by the same parents is primarily accounted for by the process of reproduction.

A further source of genetic variation in the individual arises from the process of mitosis, the reproduction of the body's cells. The DNA content of each cell must accurately replicate itself before division to be passed on to the newly formed cell. Given the complexity of the DNA molecule and the vast number of cell divisions that take place within the lifetime of an organism, it is obvious that "copying" errors are likely to occur. Drastic changes—provoked by radiation, chemicals, etc.—in the physical environment with which the genes interact may also provoke replication errors. Such errors change the linear order of the DNA bases and produce mutations in the genetic code. 12

The two usual sources of genetic variation are chromosomal mutations and gene mutations. Chromosomal mutations include duplication, deletion, or rearrangement of chromosome segments. Gene mutations result from a change in the stored chemical information in DNA. Such a change may include substitution, duplication, or deletion of nucleotides. The substitution of one nucleotide base for another may result in the incorporation of one wrong amino acid into the chain encoded by the gene, which affects the functioning of the protein to be made. In many cases, the effects are minor, but there are exceptions: the human disease sickle-cell anemia, for example, is the product of a single base substitution inherited from both parents. Although we talk as if a particular "gene" directly determined a specific trait, the "genetic difference" is due, not to the presence of something, but to the absence of the ability to make a specific protein, to which the organism reacts. 13

#### AREMINDER

To simplify, we have followed a textbook explanation and reduced the "gene" to little more than a protein-coding molecular sequence. It is misleading. Genes can manifest a position effect, changing if they move on to another place in the chromosome; organisms that possess mostly the same proteins and associated regulators can vary dramatically, and if genes simply code for proteins, it means that they only specify cellular composition—then, where does the complex structure of the organs come from?<sup>14</sup>

Much is still unknown, but it is certain that the great majority of human traits involve complex interactions of genes, biochemistry, environment, society, and free will. The genes, by themselves, are not determinative of the whole that is the human being. —Fr. Juan Carlos Iscara

- See Ridley, Genome, 6-9.
- For the time being, nobody knows with certitude how many genes are in the human genome. Habitual estimates ranged from 80,000 to 140,000. Scientists at Celera Genomics, the laboratory most advanced in the decoding of the genome, consider now that there are only about 35,000 to 50,000 genes in the genome's 3 billion base pairs.
- <sup>3</sup> See Campbell, Biology, 246-256.
- Campbell, Biology, 246.
- <sup>5</sup> In this case, the genes are called *alleles*.
- Except the germ-cells, which have only 23 chromosomes, and the red blood cells, which have none.
- Grace, Biotechnology, 21-22.
- Ten of these amino acids are supplied to the organism in our food, but the other ten have to be synthesized by our body. To let you recognize them the next time you read the nutritional information on your cereals box, the names of the 20 amino acids are: arginine, asparagine, aspartic acid, cysteine, glutamic acid, glutamine, glycine, histidine, isoleucine, leucine, lysine, methionine, phenylalanine, proline, serine, threonine, tryptophan, tyrosine, valine.
- <sup>9</sup> Grace, Biotechnology, 23.
- 10 Rensberger, Instant Biology.
- A protein composed by more than 50 amino acids, required for the processing of sugars.
- <sup>12</sup> Encyclopedia Britannica, "Heredity."
- <sup>13</sup> Moss, Gene, 46-47.
- Penman, What Are Genes?, 66.
- <sup>15</sup> Hayes, Human, 87.

mentioned, the most common tests do imply certain risks for the fetus between conception and birth. The desire of the parents "to know" is not proportionate to the danger imposed on the child.

The only possible exception would be that such a test is needed to prevent a definite commensurate risk of life or health, either to the child himself or to the mother. In such a case, the emergent risk for the child may be indirectly permitted—that is, intending the good of life and health to be protected by the testing, and reluctantly accepting the fact that a similar but less imminent danger is incurred. In almost every other case, though, the testing should not be performed—it is sinful to perform it.

#### On Post-Natal Testing:

Again, the moral problem is not the acquisition of knowledge, which in itself is morally indifferent. The moral problem lies in the motive or in the circumstances of the knowledge being acquired.

#### MOTIVE

Most of the moral problem lies in the motive for performing the test–in other words, why do I want the information? If the test is crucial for the decision to begin treatment, or to choose between alternative treatments, or to plan ahead for future special needs, it may be licitly performed.

In this respect, the intention of third parties commanding the performance of a genetic test must also be evaluated. There is the possibility that the information may be used for social stigmatization and discrimination. In the popular mind, genetic disorders are perceived as inevitably causing the illness to which they have been related, and so the positive testing labels a person with a disease. It may be used, therefore, to deny–unjustly–jobs or insurance, and even normal social relationships.<sup>49</sup>

#### CIRCUMSTANCES

Regarding the concrete circumstances, as the testing can be done through any somatic cell, the actual performance of the test is not likely to raise moral reservations.

The only circumstance that appears significant is the subjective state of the patient.

Information about one's future is not (...) an unqualified good. Until preventive measures or effective treatments are developed to forestall or prolong the time until the onset of symptoms, the information that one will develop a devastating condition like Huntington disease might be viewed more as an added burden than as a benefit.<sup>50</sup>

The psychological impact of this knowledge can very easily lead to anxiety, depression, despair, even suicide. Such cases have been known.

Does the patient, then, have the moral and spiritual strength to bear this burden? Does he have the Faith that alone will allow him to make sense of his suffering and give him, to endure it, a strength that is beyond the merely physical? If not, the search for and disclosure of this genetic information is imprudence—and sinful if there is a danger of its leading into grave despondency, *etc.* 

#### **On Carrier Testing:**

Again, as the testing can be done through any somatic cell, its actual performance does not raise moral reservations.

The carrier does not suffer himself from the disease, and usually a positive test only lets him know if he is at risk of passing it on to his progeny. If the guiding *intention* is to resort to contraceptive practices, the testing is illicit.

#### GENE THERAPY

#### GENERAL NOTIONS

The therapeutic treatment of genetic disorders aims at the cure by genetic manipulation of some obvious defect. This "defect" cannot be merely the falling short of some arbitrarily chosen or imposed "optimal" state–it must be the true lack of the biological minimum required by the organism to survive on its own, without being constantly in great suffering.<sup>51</sup> Once the precise molecular defect has been identified, the genetic disorders can be neutralized by the application of appropriate drugs or through dietary changes. On occasion, surgeons can counteract the consequences of a defective gene by using bone marrow or kidney transplants. In other cases, surgical repair of physical defects can be very effective treatment. Some other genetic defects can be treated even prenatally, through medication or even through fetal surgery.<sup>52</sup> When these procedures have proven to be ineffective in a particular case, the next step will be to attempt gene therapy. Although it is already practiced, advances have been slow until now. Much of what follows is still in the realm of unfulfilled hopes, but the development of the technology to achieve it is already speeding ahead. Moral reflection is then necessary to brace ourselves for the challenges to come.

#### **Definition:**

Gene therapy is "the intentional alteration of genes in cells or tissues in such a way as to treat or

<sup>&</sup>lt;sup>47</sup> Meilaender, *Designing*, 26-27.

<sup>&</sup>lt;sup>48</sup> Pius XII (1951), in: Solesmes, *Human Body*, 153 (n.254).

<sup>49</sup> Rodriguez, Social, 29-31.

<sup>&</sup>lt;sup>50</sup> Center for Bioethics, *New Frontiers*, 8.

<sup>51</sup> Spaemann, Genetic Manipulation, 348.

<sup>&</sup>lt;sup>52</sup> Encyclopedia Britannica, "Genetic Engineering: Treatment."

prevent an inherited disorder, or to make another pathological condition more amenable to treatment."53

Gene therapy is being developed for the treatment of diseases such as cystic fibrosis, coronary artery disease, various types of cancers, hemoglobin diseases, muscular dystrophy, Huntington's chorea, and even AIDS. A disease does not necessarily have to be genetic for gene therapy to be helpful, but genetic diseases are, for the time being, the focus of these experimental efforts.<sup>54</sup>

#### Kinds of Gene Therapy:

Two kinds of gene therapy are feasible. The first, somatic cell gene therapy, attempts to heal the disease by transferring the missing gene sequences into the cells of the diseased tissues. The second, germ-cell gene therapy, attempts a more radical cure in that it tries to "correct" the genetic defect either before the conception (in the sex cells of the parents), or before the cell differentiation in the zygote.

#### GENERAL MORAL ASSESSMENT

The genome is a part of our bodies. As such, it is not in principle untouchable.<sup>55</sup>

A strictly therapeutic intervention whose explicit objective is the healing of various maladies such as those stemming from deficiencies of chromosomes will, in principle, be considered desirable, provided it is directed to the true promotion of the personal well-being of man and does not infringe on his integrity or worsen his conditions of life. <sup>56</sup>

Every potential use of gene therapy has to be separately subject to a moral assessment.

It may be that there are no morally acceptable uses of this technology either now or in the foreseeable future. If that is the case, then there is no reason to go ahead with the technology and it is appropriate to enact legislation to prohibit it.<sup>57</sup>

## SOMATIC CELL GENE THERAPY

#### DEFINITION

Somatic<sup>58</sup> cell gene therapy is "the genetic modification of body cells of an organ system of an individual person, to prevent the development of an inherited disorder, or to treat an existing disease."<sup>59</sup> The procedure consists, as we have said, in the introduction of a gene into somatic tissue, that is, into any cell of the body, so that its product may alleviate the defect caused by the absence or malfunction of a vital gene product. This alteration affects only the individual on whom it is performed and, usually, only the genetic information in the cells of the diseased organs and tissues.

#### MORALASSESSMENT

Somatic gene therapy seems to be, in itself, morally permissible. As a response to the medical needs of the person, it does not differ in principle from any other forms of medical treatment (administration of drugs or of biological compounds, cell and tissue transplantation, *etc.*). The corrected gene is used either as a replacement of a malfunctioning element, or as a pharmacological agent.

According to Catholic doctrine, it is not only permissible but also commendable as a work of mercy—and in some cases even obligatory both in justice and in charity—to alleviate pain and to cure and prevent diseases by physical interventions upon the human body, either by surgery or through medication.

Consequently, there cannot be any substantial objection to the performance of such interventions in the human body at the molecular level rather than at the external level of the organs—both are bodily interventions with a therapeutic intent, subject to the same usual moral restrictions.

Neither can one object to the performance of such interventions at an earlier stage of development of the illness or defect, that is, as it appears in the embryo rather than in the adult. This is only an issue of timing. Once the human being has been conceived, the therapeutic modifications of his genome affect only his body, are beneficent for the whole of his being, and do not affect his continued existence as the same individual, <sup>61</sup> any more than a blood transfusion or kidney transplant upon an adult affects his identity.

The moral concerns will center on the guiding intention and the surrounding circumstances of such procedure.

#### INTENTIONS

On the side of the intention, it does not seem to arise any moral objection, because the general intent is therapeutic, that is, to heal. Any somatic alteration without this therapeutic intention will have to be regarded as "enhancement," about which we will talk later.

<sup>&</sup>lt;sup>53</sup> Working Party of U.K. Catholic Bishops Joint Commission on Bioethical Issues, quoted in May, *Catholic*, 215-216.

<sup>&</sup>lt;sup>54</sup> Rae, *Moral*, 176.

<sup>55</sup> Watt, *Human*, 267.

<sup>&</sup>lt;sup>56</sup> John Paul II (1983), Address.

<sup>57</sup> Rae-Cox, Bioethics, 115.

<sup>&</sup>lt;sup>58</sup> From the Greek *soma*, body–it refers to what belongs to the body.

<sup>&</sup>lt;sup>59</sup> Moore, Gene Therapy, 244.

<sup>&</sup>lt;sup>60</sup> Spaemann, Genetic Manipulation, 348; Watt, Human, 269; Moore, Gene Therapy, 244; Rodriguez, Social, 36.

<sup>61</sup> Watt, Human, 268.

(continued from p.16)

CIRCUMSTANCES

#### **Proportion of risks to benefit:**

Any medical procedure which entails risks for the life or physical well-being of the patient is permissible if the risks are proportionate to the benefits that are reasonably expected to be obtained.

Somatic gene therapy is still experimental, *i.e.*, not yet standard procedure. The foreseeable risks must be properly evaluated and weighed in contrast to the expected benefits for the patient. If performed, it must be reserved, therefore, only for very serious (*i.e.*, lifethreatening or gravely disabling) diseases for which there is no existing or effective alternative treatment, and only insofar as the essential wholeness of the individual is preserved. <sup>62</sup>

#### Immoral procedures:

No objective, even though noble in itself, such as the foreseeable advantage to science, to other human beings or to society, can in any way justify experimentation on living human embryos or fetuses, whether viable or not, either inside or outside the mother's womb.  $^{63}$ 

The research to develop any effective gene therapy will necessarily imply experimentation with human embryos. These embryos, from the moment of their conception, are human persons. The voluntary destruction of an innocent human being is murder, equally forbidden by divine and natural law, and usually by the just civil laws in agreement with those fundamental laws. The genetic research that requires the destruction of the embryo is, then, murder.

#### **Scandal by participation:**

As the research leading to the development of the procedures has most certainly involved the murder of human beings, the acceptance of this kind of therapy might seem to condone the means by which it was developed. It would be an implicit denial of the sanctity of life.<sup>64</sup>

Obviously, the danger of scandal decreases in proportion to the increasing remoteness from the initial, sinful experimentation–provided that no new sinful acts are perpetrated to administer the therapy. Even so, strict vigilance is due to avoid such scandal.

## GERM-LINE CELL GENE THERAPY

NOTIONS

Germ-line therapy is the intentional alteration of germ-cells (sperm and egg, or their predecessors). At present, it appears to many as the only realistic hope of finding a treatment or cure for diseases that do their

damage in the earliest stages of embryonic development.

#### **Methods**

Two technically feasible methods are proposed:

1) By the genetic alteration of the zygote<sup>65</sup> at a very early stage of development, before the process of cell differentiation and the consequent development of the body organs. It would seem that this method is similar to somatic gene therapy, only performed at an earlier stage of development of the subject; there is, though, the all-important difference that the genetic alteration at this early stage will affect all the cells of the body and therefore it will be transmitted to all descendants of the subject. Moral objections already arise to the use of this method.

2) By the transfer of normal DNA into the gametes (sex cells). Here lies the main moral question—is the performance of this procedure "playing God"? In other words, is it a usurpation of what should be exclusively under God's dominion? And if not, could it be forbidden by any other moral considerations?

#### MORALASSESSMENT

#### **By Object:**

If somatic gene therapy is licit, then there does not seem, in principle, to exist any major reason why correcting a defect that will undoubtedly affect future generations should not also to be considered morally permissible–and even praiseworthy.<sup>66</sup>

On the other hand, a good number of theologians and ethicists, Catholics and non-Catholics alike, consider that it should never be performed. Let us reflect, then, on the objective nature of the action proposed.

Is germ-line therapy an interference with "nature," that is, interference against God's purposes, as manifested in the natural order? It does not seem so.

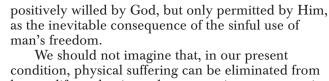
All human activity that produces changes that otherwise would not have happened could be said to "interfere," in the sense that it bypasses an obstacle put there by nature. In practice, we constantly interfere in this manner, without any moral qualms—we use glasses, we take medication, we perform surgery to repair congenital defects. Such interventions do not infringe on the integrity of the subject, of his nature, but are attempts to repair what—if unchecked or transmitted—will obstruct his functional integrity. In this light, then, germ-line therapy does not appear to differ substantially from such interventions, unanimously and rightfully perceived as morally permissible.

Physical suffering, like disease and death, is a consequence of the rebellion of sin, and as such, it is unnatural and disorderly. Such evil has not been



(Top) Human Genome Project.A researcher uses lasers to track genes. (Inset) Specific genes can be identified on specific chromosomes

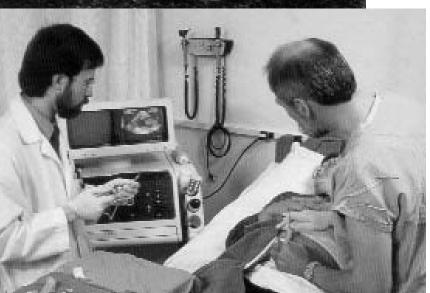
(Middle) Human chromosomes. (Bottom) Amniocentesis allows doctors to check for abnormalities and serious diseases that might affect the fetus.



We should not imagine that, in our present condition, physical suffering can be eliminated from human life or that it can have no point or purpose in our lives. Nor should we suppose that such suffering must be eliminated by any means available to us, for a good end does not justify any and every means. <sup>67</sup> But there is a duty to preserve life and health, and also to avoid and to fight illness, pain, and suffering. To will health–ours or another's–and to strive to attain it is a serious act of obedience to a grave command of God.

We must remember that the genome is not the essence of life. It is matter-fundamental, complicated, awe-inspiring, and elaborately coded-but matter nonetheless. To treat it as matter-over which we are agreed that God has given man dominion to use and administer-is not in itself sacrilegious.

Objectively speaking, then, germ-line gene therapy appears as morally licit-objectively, that is, in



May, Catholic, 219.

<sup>63</sup> Congregation for the Doctrine of the Faith, *Donum Vitae*.

<sup>64</sup> Watt, Human, 259.

The cell that is the product of fertilization, that is, of the fusion of the nucleus of the egg with the nucleus of the sperm. In biological terminology, the developing organism is called a zygote during the first week after fertilization, an embryo from the second to the eighth week of development (that is, from the implantation in the uterus to the beginning of the development of the major organ systems), and a fetus from the ninth week until the time of birth.

<sup>&</sup>lt;sup>6</sup> Rae, Moral, 176; Watt, Human, 256-257.

<sup>&</sup>lt;sup>67</sup> Meilaender, Bioethics, 8.

itself, abstracting from all concrete circumstances and intentions that will in practice surround it.

#### **By Circumstances:**

As we have said, together with the question of the objective morality of gene therapy, consideration has also to be given to the morality of its actual performance—that is, to the concrete circumstances that surround it, and to the intentions of subjects and physicians alike. Particularly when the concrete performance of germ-line gene therapy is considered, the moral arguments against it appear more clearly defined and articulated, our doubts vanish, and the moral conclusion appears in all evidence.

#### UNKNOWN AND POSSIBLY IRREPARABLE RISKS

As we have said, any medical procedure is permissible if the risks it entails are proportionate to the benefits that are reasonably expected to be obtained.

In the case of *germ-line therapy*, given how much molecular biologists still do not understand about the genome itself and the complexity of its interactions, the risks inherent in a genetic alteration for future generations are much greater and largely unforeseeable. If such alterations in the self-perpetuating germ-line produced unintended harmful effects in our descendants, some effects could be reversed by further manipulations, but perhaps some others could not be stopped.<sup>68</sup>

As it is very difficult to see how we can effectively test the possibility of harmful effects down the generations, this objection provides, by itself, sufficient moral grounds to ban any attempt at germline gene therapy.

#### IMMORAL PROCEDURES

Germ-line therapy is most likely to occur in the context of *in vitro* fertilization or similar techniques. In that case, it will be affected by those techniques' fundamental immorality, that is, by the perversion of the order of nature willed by God, by the separation of the procreative and unitive ends of marriage, <sup>69</sup> to which will have to be added the sins usually committed to obtain the sperm for the procedure.

Helen Watt<sup>70</sup> has shown that even if in some protocols sexual intercourse may enter in combination with germ-line therapy, the actual procedures can very easily violate the integrity of the reproductive process. The moral concerns arise in relation to feasible procedures dealing with the fragmentation or substitution of reproductive cells, for example the replacement of defective spermatogonia<sup>71</sup> by those of another man, or the "manufacture" of healthy eggs with parts of different women's eggs. As all these procedures introduce a third individual in the process of generation, their immorality is identical to that of

heterologous artificial fertilization <sup>72</sup>-that is, sinfully contrary to the unity of marriage and conjugal fidelity.

Let it not be forgotten that only procreation of a new life according to the will and the plan of the Creator carries with it, to an amazing degree of perfection, the realization of intended aims. It is at the same time in conformity with the corporal and spiritual nature and the dignity of the marriage partners, and with the normal and happy development of the child.<sup>73</sup>

Afterwards, in the pre-implantation screening, the embryos found to be abnormal or "substandard" would be discarded. Those redundant after implantation will be also discarded. These acts are also murder, for, as we have said above, from the moment of their conception those embryos are human persons.

Just as the Church condemns induced abortion, so she also forbids acts against the life of these human beings. (...). By acting in this way the researcher usurps the place of God; and, even though he may be unaware of this, he sets himself up as the master of the destiny of others inasmuch as he arbitrarily chooses whom he will allow to live and whom he will send to death, and kills defenseless human beings.<sup>74</sup>

#### **By Intention:**

#### Non-Therapeutic intent

If the intent is not therapeutic, the procedure is not morally permissible.

In virtue of the principle of totality, the individual parts of the body can be altered only when and to the extent that such alteration is necessary for the good of the human being as a whole. That is, these interventions must aim—as Pius XII stated—"to ensure [man's] existence or to avoid, and naturally to repair, grave and lasting damage which could otherwise be neither avoided nor repaired."

#### SLIPPERY SLOPE TOWARDS EUGENICS

C. S. Lewis pointed out that "man's power over nature turns out to be a power exercised by some men over other men with nature as their instrument.... Each new power won *by* men is also a power *over* men as well."<sup>75</sup>

The danger exists that the present focus on genes that cause disease and disability, combined with the possible acquisition of the ability to modify the germline, may shift the overall aim from therapy to eugenics. That is, the very real danger that these genetic interventions will cease to aim at the healing of the sick, and aim instead to the selective breeding of human beings, of a "better" human race—an aim dominated by uncontrolled, arbitrary notions of "improvement" and "normality."

#### A CONCLUSION

Moral theologians—at least the reasonable, sensible ones—agree that, even if genetic interventions in the germ-line may be in themselves morally permissible, "the problems and risks raised by [the concrete application of] germ-line therapy are such as to provide serious grounds for thinking that it should never be carried out."

We have the certainty that man-in our present fallen state-is not capable of making good use of this technology, of handling it virtuously. And that therefore, even if much good may certainly come out of it, the potential for evil is so horrifying that man should not use this power.

The germ-line must be left untouched. If we tinker with the germ-line, even for theoretically moral uses, *dehumanizing abuses* will inevitably follow. Once a threshold is crossed, there is no turning back. The sense of unbound, unlimited power stirred by the possibility of altering the human genome will also lead to a more perverted notion of nature and of man, with all its consequences: discrimination, marginalization, the commodification of human life, *etc.* 

The risks for the future of mankind are simply too great to allow it.

#### GENETIC ENHANCEMENT

#### DEFINITION

Genetic enhancement is the expected improvement or change, by genetic engineering, of characteristics like size, skin color, intelligence, longevity, etc. Somatic enhancements are already possible, such as the genetic alteration to produce growth hormones, to enhance height for basketball....Germ-line is-for the time being-referred to only as therapy, but once it is feasible and legal, pre-conception enhancement will not be far away.

Some scientists are already blurring the dividing line between therapy and enhancement, by proposing germ-line interventions as a means to make us physically fitter and more resistant to diseases, intellectually alert, emotionally stable...

#### MORALASSESSMENT

Such attempts, on the purely natural level, fail to appreciate the complexities of human development, and on a higher level, this time, yes, they trespass on the dominion of God by trying to manipulate the very natural characteristics of man.

There is also the possibility of a more frightening scenario (more frightening because it could affect us much more closely)–the *arbitrary imposition of ambiguous or imaginary standards of "normality,"* either by persuasion or by straightforward coercion.<sup>78</sup> Which

would be the criteria to establish that some traits are better than others? Many are simply subjective appreciations, and future environmental changes may make some of today's changes unadvisable. <sup>79</sup> And perhaps more important, who will decide which traits are "desirable" and which are not? The potential for the violation of fundamental human rights—the inalienable rights granted by God to each man—is immeasurable.

Apocalyptic exaggeration? If you say so... But familiarity with man's fallen nature tells us that curiosity and pride will ensure that whatever becomes technically feasible, it will be put into practice by someone, somewhere, and, regardless of moral or legal restrictions, it will be abused–Doctor Frankenstein all over again. Scientists have proved to be highly unreliable in disciplining themselves....

Lee Silver, professor of molecular biology at Princeton, gleefully gives us a glimpse of a world utterly changed by human genetic manipulation.

The GenRich [those who have the means to tap the gene banks to "improve" themselves and their progeny]—who account for 10 percent of the American population—all carry synthetic genes. All aspects of the economy, the media, the

- 68 Rae, *Moral*, 176.
- <sup>69</sup> See Iscara, *Immorality*, 13.
- <sup>70</sup> See Watt, *Human*, 263-264.
- <sup>71</sup> Sperm-producing cells in the testes.
- "Heterologous artificial fertilization" means that human conception is artificially achieved by the use of gametes coming from a donor other than the spouses joined in marriage. See Congregation for the Doctrine of the Faith. *Donum Vitae*, 22.
- <sup>73</sup> Pius XII (1949), in: Solesmes, *Human Body*, 118-119 (nn.177-179).
- <sup>74</sup> Congregation for the Doctrine of Faith, *Donum Vitae*.
- <sup>75</sup> "The Abolition of Man," quoted in Meilaender, *Bioethics*, 43.
- "Eugenics," meaning "well-born," is a term popularized in 1883 by Sir Francis Galton, a convinced Darwinist, to refer to his proposal to improve the human race by selective breeding, using individuals with the desirable characteristics—which, of course, were those of the Victorian upper class. Only thus he expected civilization to survive. His ideas found extensive support mainly in USA and England, at least until the Second World War.
- <sup>77</sup> May, Catholic, 219.
- <sup>78</sup> History manuals may be usually silent about it, but it is a fact. Charles Davenport, following Galton's theories and with the assistance of the Carnegie Institution, John D. Rockefeller Jr. and Mrs. E. H. Harriman, established in 1904 the "Eugenics Record Office" on Long Island. He recruited assistants from Ivy League schools and sent them into the slums of New York and New Jersey, to discern-with scant training, by sight alone-hereditary undesirable conditions, such as "dementia," "shiftlessness," "criminalism," "feeblemindedness" and "mental defects." Shoddy scientific method? Of course! But that did not prevent the data collected from becoming the major resource for two legislative programs which were the cornerstones of the US eugenics policies: the involuntary sterilization laws of the 1920's and the Immigration Restriction Act of 1924. The laws allowed the judges to impose compulsory sterilization on "hereditary criminals" and the "genetically defective"; and they were often extended to include sexual perverts, drug addicts, alcoholics, epileptics, and those deemed ill or degenerate. Although the laws were not consistently enforced, by 1935 some 20,000 people had been sterilized. The Immigration Restriction Act intended, in turn, to impede the immigration into the USA of members of ethnic groups considered to have a high proportion of "hereditary defects."-See Hubbard-Wald, Exploding, 17-22.
- <sup>79</sup> Rodriguez, *Social*, 36.

entertainment industry, and the knowledge Industry are controlled by members of the GenRich class....Naturals [those without any genetic "enhancement"] work as low-paid service providers or as laborers....The GenRich class and the Natural class will become entirely separate species with no ability to cross-breed....In a society that values individual freedom above all else, it is hard to find any legitimate basis for restricting the use of reprogenetics....I will argue [that] the use of reprogenetic technologies is inevitable. It will not be controlled by governments or societies or even the scientists who create it. There is no doubt about it: whether we like it or not, the global marketplace will reign supreme.<sup>80</sup>

# SUMMARY OF MORAL CONCLUSIONS

The back-and-forth movement of the moral reflections laid out above perhaps risks obscuring the conclusions we have arrived at. Let us, therefore, summarize here these conclusions, rounding them out with the addition of a few details and examples.

#### GENETIC TESTING

PRE-CONCEPTION TESTING:

## Gametes (ovum and sperm) testing is morally illicit.

- The testing of the gametes is of limited benefit for the progeny, since the meiosis in the process of production of ova and sperm will make each one of them slightly different from the others. The testing of the sperm has the added malice of the sin usually committed for its retrieval.
- Moreover, an added malice may be given by the intention of the subjects to practice contraception if the tests are positive for genetic disease.

POST-CONCEPTION TESTING:

## Genetic testing of the fetus in utero is morally illicit.

● It is forbidden because of the usual danger of death or malformation for the unborn child, inherent in the test itself. The genetic information, once acquired, does not seem to have any licit beneficial use for the child. Therefore, the simple desire of the parents for useless information (that is, information they are not allowed to act upon) is not a sufficient reason to impose such risks on him.

- Death or malformation is a risk, however, not a certainty. Therefore, a possible exception to the rule will be the extraordinary case when certain knowledge of the parents' genetic disorder and its consequences could constitute the aforementioned "sufficient reason." Only if such a test could help to prevent an immediate and commensurate danger of death or grave disability by allowing the early administration of medical treatment, would it be lawful.
- In frequent cases (today far too frequent!), there is the added malice of the murderous intention to abort the child if the test is positive for the genetic disorder

## Genetic testing of the embryo in vitro is equally unacceptable.

- The reasons are, as in the previous case, the common danger of death or malformation, and the possible abortive intention.
- Moreover, if this kind of testing is contemplated, it means that it is to be performed in the context of in vitro fertilization, which is in itself morally illicit.

POST-NATAL (CHILD AND ADULT)
TESTING:

## Genetic testing is in itself morally permissible...

 There is no physical danger for the patient in the performance of the test, and the therapeutic benefits greatly compensate for the inconvenience.

## ...but it may become illicit for its motive or the subjective condition of the patient.

- That is, it is a sin if the test is performed to decide either the patient to commit suicide, or to decide a third party, who has commanded the test, to "administer" euthanasia.
- It is a sin, also, if the patient or a third party, while not intending initially suicide or euthanasia, imprudently expose themselves-by the performance of the genetic test-to the danger of despair and its homicidal consequences.

#### GENETIC THERAPY

SOMATIC CELL GENE THERAPY:

## The therapeutic genetic modification of cells and tissues is morally permissible.

• In itself, objectively speaking, it is to be considered as an extension of traditional medical treatments, and it is therefore morally permissible.

## But it may be rendered illicit by immoral circumstances or intentions.

• But the goal intended and the concrete circumstances in which it is performed may very easily render it immoral, that is, a sin-if there is no genuine therapeutic intent, if the risks are excessive in proportion to the benefits, if there are alternative treatments available which do not imply such risks, if there is scandal by the apparent cooperation with the immoral research, etc.

GERM-LINE CELL GENE THERAPY:

## Genetic interventions in the zygote or in the gametes are morally illicit.

- The concrete circumstances are such as to forbid even the therapeutic intervention, because the artificial reproductive procedures in which context these interventions would be unavoidably performed are fundamentally immoral (experimentation with human embryos, in vitro fertilization, discarding of non-implanted embryos,
- Moreover, the lack of knowledge of the long-term consequences of alterations of the genome-and the impossibility to foresee all of them fully-also renders those alterations illicit.
- In the end, it should not be performed, or even attempted, because of the impossibility to prevent abuses once we have started tinkering with it.

#### GENETIC ENHANCEMENT

## Non-therapeutic genetic interventions are all illicit.

● The justification of the intervention in the genome is the therapeutic intent—that is, to cure, or at least diminish the symptoms, of a genetic disease. "Enhancement," therefore, which is not therapeutic but is simply an unnecessary tampering with the genome, prodded either by the blasphemous desire

- to "improve" on human nature, or by baser motives such as vanity, recklessness, greed, is illicit by intention.
- It is also the beginning of the "slippery slope" towards an arbitrarily imposed eugenic "ideal," which will in turn originate innumerable violations of the God-given, fundamental rights of the human person.

### **PANDORA'S BOX**

Any questioning of scientist-backed, mediapopularized innovations brings out howls of abuse against any poor soul that professes it is confused and frightened, and more than a bit doubtful, about the good to be brought about by such "progress."

How do we dare—you may ask—to spell out our doubts in the face of the wondrous advances of modern genetics?

We are not opposed, in principle, to the advance of science nor to the introduction of new technologies. This said, we hurry to add that we are very much opposed to the mistaken modern belief that technologies are morally neutral, that is, completely independent from any moral rule. That whatever can be technically done, it should be done, without any regard to "extraneous," "non-scientific" considerations.

The technologies may be, in their abstract definition, morally indifferent, but their exercise takes place in the real world—that is, they are initiated with particular goals in mind and performed in concrete circumstances of place, time, persons, tools, *etc.* Insofar as these concrete applications of the technology proceed from the free will of man, who chooses whether, why, and how to employ them, they are subject to the moral law—a stable, unchangeable law beyond the wavering of our hopes and desires—and according to it they are to be judged either as good or evil.

It is necessary to remember this because some technologies do have the potential to unleash such power that their use—with the inherent logical progression of their effects—may result, in the end, in more harm than good. It is in this respect that recently developed technologies bring to our mind the mythological warning of Pandora's box.

In Greek legend, Zeus, the king of the gods, determined to counteract the blessing Prometheus had recklessly bequeathed to mankind. He accordingly commissioned Hephaestus, the craftsman-god, to fashion a woman out of earth, upon whom the gods bestowed their choicest gifts. Zeus also gave her a closed jar-"Pandora's box"-in which he enclosed all manner of miseries and ills, and sent her to dwell

<sup>80</sup> Lee Silver, Remaking Eden, quoted in Hayes, Human, 96.

among men. Epimetheus, Prometheus' brother, was dazzled by her beauty and made her his wife. Once in her new home, Pandora, moved by curiosity and expecting to find more of the divine gifts, opened the jar, from which all the hidden evils flew out over the earth. Hope alone remained inside, the jar's lid having been shut down before she could escape....

Are we there? Oh, yes. The box has already been opened, and it is perhaps too late to try to close it. Scientists, by engineering "ANDi," the monkey with the jellyfish gene,

have taken another step towards doing what scientists usually say that no scientist would ever want to do—use genetics to change, improve or enhance our children. Sticking genes into eggs and growing a healthy monkey means that someday scientists could and most

likely would insert genes into human eggs to try to make kids smarter, stronger, faster, healthier or happier than their parents.  $^{81}$ 

We have an uphill battle ahead. Why a battle and why uphill? For three reasons.

*First*, the promises are far too great. They do not have to do with some external chattels, but with something deep within us—our fear of pain, anxiety, illness, deformity, and ugliness, our constant effort to ward off aging and even death itself. Who can resist such a lure?

**Second**, there are fortunes to be made from genetic research. Corporations and universities compete with one another to hold patents to whatever they have genetically engineered, foreseeing that people will, in turn, tussle with one another for the opportunity to buy what they offer. If there were long lines outside computer stores, throughout all night, to have the opportunity to be one of the first to buy and try Windows 98, what will people not do to buy what can give them and their children a go at being smarter, stronger, happier...?

*Third*, there is no compelling, higher motive to keep most of our contemporaries away from such enticements. Whatever little faith is left, even among

many Catholics, is of a sentimental, subjective kind. There is no sense of sacrifice, and suffering appears as the ultimate evil, to be avoided at all costs. Moral reflection has also become of a subjective temper–very few still hold that there are absolute moral norms, whose obligation is independent of our whims and desires.

The present trend, therefore, cannot be easily reversed, and, at this stage, it has become humanly impossible to reject all and every kind of genetic engineering. Some uses are undoubtedly beneficial, such as the possibility of discovering and treating gravely disabling diseases before their full onset, the development of pharmaceutical products, the mending of our ailing bodies, *etc.* We must draw the line, though, at germ-line interventions and vain "enhancements," at "transgenics," the combination of genes from different species to create unnatural living beings, and at "eugenics," the "improvement" of the human race.

As it happened before with nuclear power, the realization that the powers granted by technological advance must be harnessed to protect the very existence of mankind will come afterwards, when much damage has been recklessly inflicted. The law of unintended consequences is always valid. In the past, that realization came after Hiroshima and the threat of atomic war and the fear that led us to have fall-out shelters in our basements, after Chernobyl and pollution and the puzzle of what to do with tons of nuclear waste.... The same will happen with the "genetic power" now unleashed-but this time the consequences of scientific recklessness will not be so easily repaired. 82

Hope still remains. God still has the last word. In the meantime, we pray, we teach and warn, and we oppose. May He, to Whom all life belongs, help us.  $\Omega$ 

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<sup>81</sup> Caplan, Rules, 42.

<sup>82</sup> See Rifkin, Biotech Century, 227-237.

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