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What Sort of People Do We Want - The Ethics of Changing People through Genetic Engineering

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WHAT SORT OF PEOPLE DO WE WANT? THE ETHICS OF CHANGING PEOPLE THROUGH GENETIC ENGINEERING

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Within the last decade, genetic engineering has changed from being a relatively esoteric research technique of molecular biologists to an application of considerable power, yet one which raises widespread public concern. In this article, I first briefly summarize the principles of genetic engineering, as applied to any organism. I then concentrate on humans, reviewing both progress to date and possible future developments. Throughout, my particular focus is on the ethical acceptability or otherwise of the technology.

I restrict myself to cases where humans are themselves being genetically engineered. This means, for instance, that I do not cover such topics as xenotransplantation (when animals are genetically engineered to make them suitable for transplantation into humans) and the issues resulting from the production of such products as genetically engineered human growth hormone, α1-antitrypsin, or vaccines (when micro-organisms, animals, or plants are genetically engineered to produce human proteins). Nor do I cover cloning, which deserves an article all to itself.

My three main conclusions are as follows: First, somatic gene therapy (in which genetic alterations are made to the non-reproductive cells of an individual for intended medical benefit) is ethically fairly unproblematic and likely to be accepted by the great majority of people. However, its scope is more limited than is often supposed. Second, germ-line therapy (in which genetic alterations are made to the reproductive cells of an individual for intended medical benefit for him/herself and his/her descendants) is currently too risky to be allowed. However, this will probably not always be the case. Third, the use of either somatic or germ-line modification to enhance human traits such as person-

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ality, behavior, or intelligence, is highly controversial. At present it is probably best to outlaw such practices.

I. PRINCIPLES OF GENETIC ENGINEERING

As is nowadays widely known, every organism carries inside itself what are known as genes. These genes are codes or instructions: they carry information which is used to tell the organism what chemicals it needs to make in order to survive, grow, and reproduce. Most genes make proteins such as keratin (which is found in hair and nails), actin and myosin (both found in muscles), and all the various enzymes that control the rates at which the chemical reactions in organisms take place. Genetic engineering typically involves moving genes from one organism to another. The result of this procedure, if all goes as intended, is that the chemical normally made by the gene in the first organism is now made by the second.

A. *The Basic Practices of Genetic Engineering*

Suppose we want a species to produce a protein made by another species. For example, we might want a bacterium to produce human insulin so as to be able to collect and then give the insulin to people unable to make it for themselves. The basic procedure, using genetic engineering, involves the following steps:

1. Identify the gene that makes the protein we are interested in.
2. Transfer this gene from the species in which it occurs naturally to the species in which we want the gene to be.[1]

The first of these steps is more difficult than it may sound. Even a bacterium has hundreds of different genes, while animals and plants have tens of thousands or more. Humans probably have around 80,000 to 100,000 genes.[2] Nowadays, though, there are a number of ways of identifying the gene that makes the protein in which one is interested.

Two different types of approaches can be used to carry out the second step, namely transferring this gene from the species in which it occurs naturally to the intended species recipient. One involves the use of a vector organism to carry the gene; the

1. *See generally* DESMOND S.T. NICHOLL, AN INTRODUCTION TO GENETIC ENGINEERING (1994).
2. *See id.* at 146.

other, called vectorless transmission, is more direct and requires no intermediary organism.[3]

A vector carries genetic material from one species (the donor species) to another (the genetically engineered species). Genetic engineering by means of a vector involves three steps:

1. Obtain the desired piece of genetic material from the donor species.
2. Insert this piece of genetic material into the vector.
3. Infect the species to be genetically engineered with the vector so that the desired piece of genetic material passes from the vector to the genetically engineered species.[4]

B. *Examples of How Genetic Engineering Is Carried Out*

An example of genetic engineering by means of a vector is the infection of certain plants by genetically engineered forms of the bacterium *Agrobacterium*. *Agrobacterium* is a soil bacterium that naturally attacks certain plants, infecting wounds and causing the development of swellings known as tumors. In 1977, it was found that the tumors were due to the bacterium inserting part of its genetic material into the host DNA. This means that if foreign DNA is inserted into the DNA of *Agrobacterium*, the *Agrobacterium* can in turn insert this foreign DNA into the genetic material of any plants it subsequently attacks. This property can be used by scientists to produce new crops.

Viruses can also be used as vectors in genetic engineering. For example, retroviruses have been used in genetic engineering research on humans. Retroviruses are good candidates for this approach as they have millions of years of experience at inserting their genetic material into that of a host. A number of diseases are caused by mutations in genes expressed in bone marrow cells—the cells that give rise to our blood cells. Retroviruses have been used in attempts to insert a functional copy of the faulty gene into these bone marrow cells. The aim is to ensure that all the blood cells that descend from these bone marrow cells are healthy.[5]

One problem with this approach, which limits the number of diseases on which trials are being run, is that retroviruses only

3. *See* Michael Reiss, *Biotechnology, in* 1 ENCYCLOPEDIA OF APPLIED ETHICS 319, 321 (Ruth Chadwick ed., 1988).

4. *See id.*

5. *See* Kohnoske Mitani & C. Thomas Caskey, *Delivering Therapeutic Genes—Matching Approach and Application*, 11 TRENDS IN BIOTECH. 162, 163-64 (1993).

infect dividing cells. Many human diseases, for example those of the nervous system, are not caused by mutations in dividing cells. A second problem is that, as so often in genetic engineering, there is no control presently available as to where the gene is inserted in the human chromosomes. Instead, the retrovirus inserts the desired gene more or less randomly.[6] This has two consequences. First, the new gene may not be as effective as when it is located in its normal place. This is because genes often work best only if they are situated close to certain other genes which help turn them on and off. The second, and more dangerous, possible consequence is that the new gene may, by mistake, be inserted into an important gene, for example tumor-suppressor genes which help prevent cancers. Disruption of the activity of a tumor-suppressor gene by the insertion of a new gene through the activity of a retrovirus has been shown in monkeys to lead on occasions to the development of cancer.[7]

For these reasons, researchers are experimenting with other viruses. For example, adenoviruses are being used in attempts to insert functional copies of the gene, which, in its faulty form, causes cystic fibrosis in humans. Adenoviruses, unlike retroviruses, do not integrate their genes into their host's DNA. This has both advantages and disadvantages.[8] An obvious disadvantage follows from the fact that any descendants of the genetically engineered cells do not carry the functional cystic fibrosis gene. This means that once the genetically engineered cells die, the functional cystic fibrosis gene is lost with them. As a result, this approach is only likely to be effective if people with cystic fibrosis are treated with genetically engineered adenoviruses every few months. On the other hand, there is less risk of the virus inserting its genetic material into the host cells in such a way as to disrupt normal functioning or even cause cancer.[9]

One way of getting DNA into a new organism, without using a vector, is simply to fire it in via a gun, i.e., biolistic (particle-gun) delivery. The DNA is mixed with tiny metal particles, usually made of tungsten. These are then fired into the organism, or a tissue culture of cells of the organism. The chief advantage of this method is its simplicity, and it is widely used in the genetic engineering of plants. One problem, not surprisingly, is the damage that may be caused as a result of the firing process. A

6. *See* MICHAEL J. REISS & ROGER STRAUGHAN, IMPROVING NATURE? THE SCIENCE AND ETHICS OF GENETIC ENGINEERING 41 (1996).

7. *See id.*

8. *See* Myra Stern & Eric W.F.W. Alton, *Gene Therapy for Cystic Fibrosis*, 45 BIOLOGIST 37, 38 (1993).

9. *See id.*

more intractable problem is that only a small proportion of the cells tend to take up the foreign DNA.[10]

A second way of getting DNA into a new organism is by injecting it directly into the nucleus of an embryonic cell. This approach is quite widely used in the genetic engineering of animals. This method ensures that at least some of the cells of the organism take up the foreign DNA.[11]

C. *Two Fundamental Types of Genetic Engineering*

A final principle of genetic engineering is that it can take place in one of two ways—one that involves the genetic engineering of germ-line cells, the other the genetic engineering of somatic cells. Germ-line cells are the cells found, in mammals, in the ovaries of a female and the testes of a male and give rise, respectively, to eggs and to sperm. Somatic cells are all the other cells in the body.[12]

The importance of this distinction is that any genetic changes to somatic cells cannot be passed on to future generations. Changes, on the other hand, to germ-line cells can indeed be passed on to children and succeeding generations.[13] For this reason, changes to germ-line cells generally have wider ethical implications than changes to somatic cells.

II. CYSTIC FIBROSIS

Cystic fibrosis is a common genetic disease in many countries, including the United States. Someone with cystic fibrosis has severe breathing problems and typically suffers from lung infections; their digestion is poor, they may develop diabetes, and they produce abnormally salty sweat (not a problem in itself, but used historically, before the advent of modern biotechnology, as an indication that a baby had cystic fibrosis).[14]

It has long been known that cystic fibrosis is an example of an autosomal recessive condition. By "autosomal" is meant that the gene responsible is on neither the X- nor the Y-chromosomes, but on one of the other, non-sex, chromosomes.[15]

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10. *See* WILLIAM BAINS, BIOTECHNOLOGY FROM A TO Z 42 (1993).

11. *See id.* at 147-48.

12. For example, the cells of our digestive system, nervous system, cardiovascular system, lungs, and skin are all somatic. *See* ROBERT F. WEAVER & PHILIP W. HENDRICK, GENETICS 320 (2d ed. 1992).

13. *See id.*

14. *See* Stern & Alton, *supra* note 8, at 37-38.

15. *See generally* ALAN E.H. EMERY & ROBERT F. MUELLER, ELEMENTS OF MEDICAL GENETICS (8th ed. 1992).

(Humans have 44 autosomal and two sex chromosomes, women being XX and men XY.) By "recessive" is meant that an affected person has two faulty versions of the gene. In the great majority of cases this is simply because both the copy inherited from the mother and the one from the father are faulty.[16] People with one normal and one abnormal form of the cystic fibrosis gene are known as heterozygotes (the standard genetic term for an organism with two different forms of a single gene). Because the faulty copy is recessive, heterozygotes are perfectly normal and have none of the symptoms of cystic fibrosis. However, if they have children with another person who is heterozygous for the gene, there is a one in four probability that any child they have will have cystic fibrosis.[17]

The various symptoms of cystic fibrosis can be traced back to a single consequence of the faulty gene—the excessive production of abnormally thick, sticky mucus. In the lungs, this thick mucus clogs up the delicate alveoli (air sacs) and smaller bronchioles. As a result, breathing is difficult and the person is prone to lung infections. In the pancreas the large amounts of sticky mucus block the exit for the various pancreatic enzymes that normally go to our small intestines and help digest our food.[18] As a result, a person with cystic fibrosis suffers from poor digestion as the enzymes fail to reach the small intestine. In addition, these pancreatic digestive enzymes—unable to reach the gut and instead accumulating in the pancreas—may start to attack the pancreas itself. As a consequence the pancreas may literally be eaten away. As the pancreas produces the hormone insulin, which regulates blood sugar levels, people with cystic fibrosis may develop diabetes—as this results from insufficient production of insulin.[19]

In 1989, the defective gene responsible for cystic fibrosis was finally isolated on the long arm of chromosome 7.[20] This gene codes for a protein which controls the movement of chloride ions across cell membranes. The defective gene prevents the movement of chloride ions out of cells. Normally water follows these chloride ions and makes the mucus secreted by cells quite runny. In the absence of these chloride ions, less water accompanies the mucus which is consequently more sticky. This simple

16. *See id* at 2-3.

17. *See id* at 2-3, 42.

18. *See* Jane C. Davies et al., *Prospects for Gene Therapy for Cystic Fibrosis*, 4 MOLECULAR MED. TODAY 292 (1998).

19. *See* REISS & STRAUGHAN, *supra* note 6, at 203.

20. *See* Stern & Alton, *supra* note 8, at 37.

fact is probably sufficient to cause all the problems associated with cystic fibrosis.[21]

The isolation of the gene responsible for cystic fibrosis has opened up the reality of genetic screening. A simple test of a person's saliva, costing about the price of a newspaper, allows identification of carriers (people who have one healthy and one faulty copy of the gene)—though only with about ninety percent accuracy.[22] Suppose you have a close relative who has cystic fibrosis, but you don't. There is a chance that you are a carrier. You might choose to undergo screening, for example, if you are about to start a family.

Suppose you and your partner both discover that you are carriers, and the two of you are expecting a baby: there is a one in four chance that the baby will have cystic fibrosis. Genetic screening gives you the opportunity to use antenatal diagnosis to see if the baby will have cystic fibrosis or not. Using amniocentesis or chorionic villus sampling, a tiny sample of cells from the developing fetus is taken.[23] The relevant gene is examined in the laboratory and a diagnosis can be made. Three-quarters of the time the news will be good: the baby won't have cystic fibrosis. However, on a quarter of the occasions, the news will be bad: the baby will have cystic fibrosis.

At present the only option available to a couple in this position is to decide whether to continue with the pregnancy or opt for a termination. Many opt for a termination, a decision of great personal and moral significance, particularly as most people with cystic fibrosis live into adulthood.[24] Gene therapy and conventional treatment are beginning to open up new avenues of treatment.

The problems that cystic fibrosis causes for the digestive system can be controlled fairly well with drugs. However, the damage to the lungs eventually proves fatal and few people with cystic fibrosis live to be forty.[25] Somatic gene therapy offers the hope of halting, or at least slowing, the lung damage. The main steps are as follows:

1. Obtain a healthy copy of the cystic fibrosis (CF) gene.
2. Insert the CF gene into the genetic material of a convenient bacterium.

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21. *See* Davies et al., *supra* note 18, at 292.

22. *See* REISS & STRAUGHAN, *supra* note 6, at 203.

23. Both amniocentesis and chorionic villus sampling carry a small risk, on the order of 0.5 to 2 percent, of causing a miscarriage.

24. *See* REISS & STRAUGHAN, *supra* note 6, at 204.

25. *See id.*

3. Allow the bacteria to reproduce many times.
4. Remove the healthy copies of the CF gene from the bacteria.
5. Put these healthy CF genes into a vector (such as a harmless virus).
6. Use this vector to carry the healthy CF genes to the cells that line the lungs.
7. Here, the CF genes insert themselves into the DNA in these cells.
8. The CF genes then make the missing protein.
9. The missing protein then moves to the membrane that surrounds the cell.
10. Here it regulates the passage of chloride ions, allowing the mucus produced by the cell to be its normal runny consistency.[26]

Three main vectors have been tried to allow step six to take place. One approach is to use hollow membranous spheres called liposomes. The advantage of liposomes is that they easily fuse with the membranes that surround cells, thus releasing their contents into the cytoplasm of the cells. The disadvantage is that most of the genes carried in this way don't end up inserting themselves into the cell's DNA. A second approach is to use a retrovirus. Retroviruses are viruses which are very efficient at inserting genes into the cell's DNA. There is, however, a worry, that there may be an increased risk of this damaging the normal controls on cell growth. In the worst case this could conceivably trigger a cancer. The third approach is to use a cold virus. Cold viruses, of course, are rather good at carrying genes into lung cells. Unfortunately, they can also cause inflammation of the lungs, the last thing someone with damaged lungs wants.[27]

Early indications are that somatic gene therapy should be a valuable treatment, though perhaps its effects will be less spectacular than had been widely hoped. One encouraging finding is that it seems that only ten percent of the cells lining the lungs need to have the missing proteins in their membranes replaced for the lung to function normally.[28]

Before we leave cystic fibrosis, we should note that even without gene therapy tremendous advances have been made in the treatment of cystic fibrosis. Average life expectancy for people with cystic fibrosis has increased dramatically in recent years—in

26. *See* Davies et al., *supra* note 18, at 293-96.
27. *See* Mitani & Caskey, *supra* note 5, at 162-65.
28. *See* Fiona Watson, *Human Gene Therapy—Progress on All Fronts*, 11 TRENDS IN BIOTECH. 114, 116 (1993).

western countries from just one year in 1960 to five years in 1970 to ten years in 1980 to almost twenty years in 1990 and to around twenty-five years in 1995.[29] These improvements have come about partly through aggressive antibiotic regimes used to fight off lung infections, and partly through intensive, daily physiotherapy which is time consuming and can be painful.

New advances continue to be made. In 1993, Genentech published the results of clinical trials on a new drug called pulmozyme. This reduces lung infection and shortness of breath.[30] In 1995, a Cleveland team published the results of a four-year clinical trial of a new drug called ibuprofen. They found that it slows lung deterioration by almost ninety percent in children who start taking it before their teens.[31]

Advances, such as these, in conventional medicine do not of course eliminate the potential of gene therapy. However, they remind us that gene therapy may not be the only way of treating even genetic diseases such as cystic fibrosis.[32] In addition, the present work with liposomes and viruses as vectors should not be seen as a permanent solution to the problems of cystic fibrosis. Because the cells lining the lungs are shed quite rapidly, repeated gene therapy will probably be needed.[33] Nevertheless, there is a real chance that gene therapy may come to play a significant part in the treatment of cystic fibrosis, allowing many tens of thousands of people to enjoy a far better quality of life.

III. SOMATIC GENE THERAPY FOR OTHER DISEASES

I have concentrated so far on cystic fibrosis because of its widespread occurrence and because of the potential genetic engineering has to help people with this condition. However, what may have been the first successful attempts to genetically engineer humans were initially carried out in 1990, three years before trials began on cystic fibrosis.[34]

These attempts involved patients with a very rare disorder known as severe combined immune deficiency (SCID). In someone with SCID, the immune system doesn't work. As a result the person is highly susceptible to infections. Children with SCID are sometimes known as bubble babies because, until recently,

29. *See* REISS & STRAUGHAN, *supra* note 6, at 206.

30. *See* Stephen M. Edgington, *Nuclease Therapeutics in the Clinic*, 11 BIO/TECH. 580, 580-82 (1993).

31. *See Cystic Fibrosis Drug*, NEW SCIENTIST, Apr. 8, 1995, at 11.

32. *See* REISS & STRAUGHAN, *supra* note 6, at 206.

33. *See id.*

34. *See* W. French Anderson, *Human Gene Therapy*, 392 NATURE 25, 25-30 (1998).

almost the only way to allow them to live more than a few years was to isolate them in plastic bubbles. These bubbles protect the children from harmful germs but also, poignantly, cut them off from all social contact. In any event, at best the bubbles prolong life by only a few years.[35]

SCID can have a number of causes. Probably the single most common one is an inherited deficiency in a single enzyme—adenosine deaminase (ADA).[36] The first person with SCID to be treated with gene therapy was a four year-old girl named Ashanthi De Silva. She was unable to produce ADA, and in 1990 some of her white blood cells were removed and functioning versions of the ADA gene were introduced into them using a virus as a vector.[37] The improvement in her condition was remarkable. Soon she was living a comparatively normal life, attending a typical school and so on. She was no more likely to catch infections than her classmates and, on one notable occasion, when she and all her family caught the flu, she was the first to recover. At present she gets regular transfusions (every few months) of genetically engineered white blood cells, as the white blood cells live less than a year.[38] However, in addition to being treated in this way, she continues to receive conventional treatment and it is possible that this, rather than genetic engineering, is what has been of therapeutic value.

It may eventually be possible to modify so-called stem cells. Stem cells are immortal; they reside in the bone marrow and give rise to the different types of blood cells.[39] At present, however, identifying and purifying stem cells is proving difficult. If they can be genetically engineered they hold out the hope of a complete cure for SCID.

To date, many hundreds of trials for somatic gene therapy have been approved, mostly in the United States. In addition to trials on people with cystic fibrosis and SCID, somatic gene therapy is being tried for a number of other conditions including familial hypercholesterolemia, Duchenne muscular dystrophy, hemophilia, β-thalassemia, and cancers.[40] In some cases, the

35. *See* Jeffrey L. Fox, *Gene Therapy Off to a Slow Start*, 12 BIO/TECH. 1066, 1066 (1994).

36. *See id.*

37. *See id.*

38. *See id.*

39. *See* BAINS, *supra* note 10, at 300-01.

40. *See* Betty Dodet, *Commercial Prospects for Gene Therapy—A Company Survey*, 11 TRENDS IN BIOTECH. 182, 183 (1993); Jeffrey L. Fox, *NIHRAC Approves 11 Gene Therapy Protocols*, 11 BIO/TECH. 780 (1993); Watson, *supra* note 28, at 114-16.

results have been very encouraging, though progress has been slower than hoped[41] and has led to some spectacular falls (often in the wake of spectacular rises) in share prices for biotechnology companies.

IV. THE SCOPE OF SOMATIC GENE THERAPY

It is easy, given the initial successes of somatic gene therapy, to get carried away, hoping that it will soon be a cure for all our problems. It is important, however, to be clear about the potential scope of gene therapy. For a start, it should be realized that some human diseases caused by faulty genes can already be treated quite effectively by conventional means. For example, every baby born in most western countries is tested for the genetic disease phenylketonuria, though the baby's parents probably aren't aware of this. The reason is that, provided action is taken soon after birth, the harmful consequences of the condition can be prevented.[42]

A. *Treatment of Phenylketonuria Does Not Require Genetic Engineering*

Phenylketonuria is a condition which, if untreated, leads to the person being severely mentally retarded. Affected individuals often have convulsions and, in the past, were frequently institutionalized. Since the 1950s, though, it has been realized that the condition can be entirely prevented.[43] If children with the faulty gene that causes phenylketonuria are given a diet that has only small amounts of the amino acid phenylalanine, they grow up healthy and normal. This is because they lack a particular enzyme which converts phenylalanine into another amino acid, tyrosine. It is the build-up in the levels of phenylalanine that causes the problems. Keeping the levels of phenylalanine in the diet low therefore prevents the harmful consequences of the condition.[44] Such a diet is extremely boring for children and quite expensive but these are small prices to pay in light of the benefits the diet brings.

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41. *See* Anthony Meager & Elwyn Griffiths, *Human Somatic Gene Therapy*, 12 TRENDS IN BIOTECH. 108 (1994); David J. Weatherall, *The Thalassaemias*, 314 BRITISH MED. J. 1675 (1997).

42. *See* EMERY & MUELLER, *supra* note 15, at 69-73; *see also* PHILIP KITCHER, THE LIVES TO COME: THE GENETIC REVOLUTION AND HUMAN POSSIBILITIES (1996).

43. *See* EMERY & MUELLER, *supra* note 15, at 69-73.

44. *See id.*

Phenylketonuria illustrates a most important truth about human development: both genes and the environment play essential parts. True, phenylketonuria is a genetic disease in the sense that it is the result of a faulty gene. But the extent to which the disease manifests itself depends on the environment. A normal diet (i.e., normal environment) and the person is severely affected; a special diet (i.e., a different environment) and the person is unaffected. To describe phenylketonuria, or any other condition, as a "genetic disease" is, at best, a convenient shorthand. Both genes and the environment are involved in the manifestation of any trait. Shorthand is useful so long as one doesn't forget what it stands for.[45]

So, changing the environment can prevent some genetic diseases. In essence, changing the environment is how all conventional medicine works. Consider, for instance, juvenile-onset diabetes. Again, the disease is "genetic" yet its symptoms can largely—though not entirely—be prevented by regular injections with insulin. This insulin can be obtained from pigs or cows, or it can be produced by bacteria that have been genetically engineered to produce human insulin.[46] Of course, it may turn out to be the case that the best results will come from genetically engineering humans so that their pancreases produce their own insulin twenty-four hours a day. However, the fact that countless diabetics have been able to lead relatively normal lives thanks to insulin injections, instead of dying painfully in childhood or adolescence, shows how both genes and the environment play a vital role in development.

B. *Changing Single Genes Is Rarely Enough to Prevent or Cure Disease*

A second reason why we should not see gene therapy as the likely solution to all medical problems also relates to the roles played by genes and the environment. Frequent announcements in the press that the gene for breast cancer, cancer of the colon, Alzheimer's disease, or schizophrenia has been identified may appear to offer the hope for a cure. The reality, though, is often far from this.

First, knowing what causes a condition may be a valuable step in preventing it, but it is most definitely not the same thing. You may be unable to speak Russian or play the trumpet, and, if this is the case, you probably know why you can't. But knowing this is no more than the first step in helping you achieve these

45. *See* REISS & STRAUGHAN, *supra* note 6, at 209.
46. *See id* at 209-10.

ends. In the same way, knowing which of the many human genes causes a disease is a very long way from treating, curing, or preventing it. Initially, it simply offers the possibility of genetic screening.

Second, diseases such as cystic fibrosis, phenylketonuria, and sickle-cell disease are the exception, not the rule. These conditions are caused by inborn errors in single genes. However, only around two percent of our total disease load is due to errors in single genes, such as these, or to chromosome mutations such as those leading to Down's syndrome and Turner's syndrome, where the person is born with an extra chromosome.[47] The great majority, ninety-eight percent, of human disease is not like this. For a start, most human diseases have a strong environmental component, so that genetic defects merely predispose the person to develop the condition. Then, the genetic component is the result of many genes.[48]

A condition affected by many genes is called a "polygenic" condition or trait. Human skin color, for instance, is a polygenic trait. In school, students are taught a very simplified, and somewhat misleading, version of human genetics. For example, human eye color is generally taught as being determined by just a single gene. In reality, though, eye color is determined by several genes. Indeed, the vast majority of human traits are determined polygenically.[49]

A final point is that we are only just beginning to appreciate the extent to which the human body, and mind, can overcome genetic handicaps. Particular genetic mutations certainly increase the risk of an individual developing certain cancers or heart disease. Similarly, there may well be genetic mutations which increase one's risk of developing schizophrenia or depression. However, this is very different from saying that there is "a gene for breast cancer" or "a gene for schizophrenia." In the case of breast cancer, early indications are that while a mutation in the BrCA1 gene greatly increases a woman's chance of developing breast cancer, it is still the case that at least fifteen percent of women with this mutation do not go on to develop breast cancer. Further, it is probable that many women with a history of breast cancer in their family do not have a mutation in this

47. *See* John Horgan, *Eugenics Revisited*, SCI. AM., June 1994, at 92.

48. *See* Richard Strohman, *Epigenesis the Missing Beat in Biotechnology*, 12 BIO/TECH. 156 (1994); *see also* Horgan, *supra* note 47, at 92.

49. *See generally* CURT STERN, PRINCIPLES OF HUMAN GENETICS 443-67 (3d ed. 1973) (discussing mechanisms and scope of polygenic inheritance).

gene.[50] In the case of the "colon gene," a mutation in the gene accounts for only ten percent of all colon cancers, while someone with an altered form of the gene has a thirty percent chance of never developing colon cancer.[51]

The fact that most important human diseases have a heavy environmental component, are almost always affected by several genes, rather than just one, and are frequently modulated in their severity by the actions of the human body means that the scope for gene therapy is likely to be more limited than many suspect.

So far I have confined myself to what we may term "real human diseases." But what of gene therapy to affect traits such as intelligence, beauty, criminality, and sexual preference. Will this ever be practicable?

Although there are frequently reports in the popular press of "a gene for homosexuality" or "a gene for criminality" our discussion of the complexity of human disease should caution us against such simplistic notions. True, it is the case, as shown by twin studies, cross-fostering, and other evidence, that much human behavior has a genetic component to it. However, attempts to find genes for homosexuality, intelligence, beauty, or criminality are, at best, the first steps to understanding the rich and complex ways in which we behave. At worst, they are misguided attempts to stigmatize certain members of society. Part of the very essence of our being human is that we, above all the other organisms with which we share this planet, have the potential to transcend much of our biological heritage. We are more—far, far more—than our genes.[52]

V. THE ETHICAL SIGNIFICANCE OF SOMATIC GENE THERAPY

What new ethical issues are raised by somatic gene therapy? The short answer, when we are talking about real human dis-

50. *See* R. GRANT STEEN, DNA AND DESTINY: NATURE AND NURTURE IN HUMAN BEHAVIOR (1996); Phyllidia Brown, *Breast Cancer 'Too Complex' for Gene Test*, NEW SCIENTIST, Dec. 10, 1994, at 4.

51. *See* Susan Katz Miller, *'Colon Gene' Rounds Off A Brilliant Year*, NEW SCIENTIST, Dec. 11, 1993, at 4.

52. This point is argued in detail in STEVEN ROSE ET AL., NOT IN OUR GENES: BIOLOGY, IDEOLOGY AND HUMAN NATURE (1984), and in RICHARD C. LEWONTIN, BIOLOGY AS IDEOLOGY: THE DOCTRINE OF DNA (1992). *See also* MICHAEL J.A. HOWE, IQ IN QUESTION: THE TRUTH ABOUT INTELLIGENCE (1997); JANET SAYERS, BIOLOGICAL POLITICS: FEMINIST AND ANTI-FEMINIST PERSPECTIVES (1982); *Special Issue: Intelligence and Social Policy*, 24 INTELLIGENCE 1 (Linda S. Gottfredson ed., 1997); Udo Schüklenk et al., *The Ethics of Genetic Research on Sexual Orientation*, HASTINGS CENTER REP., July-Aug. 1997, at 6.

eases, is probably none. Of course, somatic gene therapy is still a very new technique, and mostly at the research rather than the clinical stage. However, there is considerable agreement about how medical research and innovative practice should be regulated in the light of ethical considerations.[53] There is little doubt that ethical considerations have so far been applied to somatic gene therapy even more stringently than to conventional medicine.

In January 1992, in the United Kingdom, the Clothier Committee produced its report on the ethics of somatic gene therapy. After carefully reviewing such considerations as the likely success of the procedure, consent, and confidentiality, the Clothier Committee's decision was that:

> We conclude that the development and introduction of safe and effective means of somatic cell gene modification, directed to alleviating disease in individual patients, is a proper goal for medical science. Somatic cell gene therapy should be regarded, at first, as research involving human subjects and we **recommend** that its use be conditional upon scientific, medical and ethical review. Although the prospect of this new therapy heightens the familiar ethical concerns which attend the introduction of any new treatment, we conclude that it poses no new ethical problems.[54]

Although the United Kingdom government waited over a year to respond, it eventually accepted this recommendation. Other countries too, including, of course, the United States, have permitted somatic gene therapy. Because somatic gene therapy typically involves giving a person healthy DNA to override the effects of their own malfunctioning DNA, it has been pointed out that this is not very different from giving a person a blood transfusion or organ transplant. Of course, some individuals may choose not to have a transfusion or transplant, but very few people suggest forbidding them entirely.

It is also the case that somatic gene therapy has the potential to reduce the number of ethically problematic decisions. For example, at present the only "solution" offered to a woman who

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53. *See* TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS (4th ed. 1994); BIOETHICS: BASIC WRITINGS ON THE KEY ETHICAL QUESTIONS THAT SURROUND THE MAJOR, MODERN BIOLOGICAL POSSIBILITIES AND PROBLEMS (Thomas A. Shannon ed., 4th ed. 1993); BIRTH TO DEATH: SCIENCE AND BIOETHICS (David C. Thomasma & Thomasine Kushner eds., 1996); IAN KENNEDY, TREAT ME RIGHT: ESSAYS IN MEDICAL LAW AND ETHICS (1988).

54. CLOTHIER COMMITTEE, REPORT OF THE COMMITTEE ON THE ETHICS OF GENE THERAPY 17 (1992).

is carrying a fetus identified as having a serious genetic disorder such as cystic fibrosis or muscular dystrophy is the possibility of an abortion. Somatic gene therapy may be able to offer a more positive way forward.

However, somatic gene therapy may, in time, raise new ethical issues. Suppose, despite what we have said about the complexities of human behavior, it does eventually transpire that somatic gene therapy could reduce the likelihood of someone being violently aggressive or of being sexually attracted to others of the same sex. What then? The simple answer is to throw one's hands up in horror and agree that such "treatments" should be outlawed. However, one problem with this response is that most countries already spend a lot of time and effort trying to get people who have been convicted of violent crimes to be less likely to commit these again. They may attend education programs or receive state-funded psychotherapy, for instance, in attempts to achieve these aims. Similarly, some psychiatrists and counselors are still prepared to work with homosexuals to help them change their sexual orientation.

These two examples (violent behavior and homosexuality) highlight two related issues. The first has to do with the social construction of disease. It is easy to assume that diseases are fixed, objective realities. A different approach is to accept that a disease is, in a sense, a relationship a person has with society. Is being four feet tall a disease? The answer tells us more about a society than it does about an individual of this height. Some conditions are relatively unproblematic in their definition as a disease. For instance, Lesch-Nyhan disease is characterized by severe mental retardation, uncontrolled movements (spasticity) and self-mutilation.[55] No cure is at present available and the person dies, early in life, after what most people would consider an unpleasant existence. It is the existence of conditions such as this that have even led to claims in the courts of wrongful life or wrongful birth where a sufferer, or someone acting on their behalf, sues either their parent(s) or doctor(s) on the grounds that it would have been better for them never to have been born.[56] However, years of campaigning by activists for people with disabilities have shown us the extent to which many diseases or disabilities are as much a reflection of the society in which the

55. *See* EMERY & MUELLER, *supra* note 15, at 78.

56. *See* Turpin v. Sortini, 643 P.2d 954 (Cal. 1982) (denying recovery for general damages in suit brought on behalf of child alleging wrongful life); Gleitman v. Cosgrove, 227 A.2d 689 (N.J. 1967) (same).

person lives as they are the product of the genes and internal environment of that person.

The second issue has to do with consent. It is one thing for a person convicted of a violent crime to give their informed consent to receive psychotherapy or some other treatment aimed at changing their behavior—though even these treatments are, of course, open to abuse.[57] It would be quite another for a parent to decide, on a fetus' or baby's behalf, to let it receive somatic gene therapy to make it less aggressive.

In an attempt to set limits on the operation of somatic gene therapy, the Clothier Committee concluded that, "In the present state of knowledge any attempt by gene modification to change human traits not associated with disease would not be acceptable."[58] Similarly, the arguments of members of a number of the world's major religions at the 1992 conference on "Genetics, Religion and Ethics" held in Houston, Texas are fairly represented by the view of George Pazin, a member of the Orthodox Church and professor at the University of Pittsburgh School of Medicine, who stated "I am all in favor of repairing God's creation with the genetic tools that we have discovered, but I shudder to think of our trying to improve upon the creation."[59] At the present time it may be difficult to be more precise than these last two quotes. However, it is worth noting that several countries officially permit abortions only on health grounds yet, in practice, offer abortion on demand. By analogy, should the use of somatic gene therapy ever become widespread it may be difficult to prevent it being used for cosmetic purposes, in much the same way that plastic surgery can be used both for life-saving and for trivial purposes.

VI. THE ETHICAL SIGNIFICANCE OF GERM-LINE THERAPY

The idea of genetic alterations to the human germ-line (so that succeeding generations are affected, rather than just the individual concerned) has been rejected by a number of religious writers and organizations,[60] as it has by many secular writ-

57. *See generally* JEREMY HOLMES & RICHARD LINDLEY, THE VALUES OF PSYCHOTHERAPY (1989).

58. CLOTHIER COMMITTEE, *supra* note 54, at 22.

59. J. ROBERT NELSON, ON THE NEW FRONTIERS OF GENETICS AND RELIGION 151 (1994).

60. In 1983, fifty-eight scientific and religious leaders signed a statement calling for the banning of all germ-line research in humans. *See* Stephen Budiansky, *Anatomy of a Pressure Group*, 309 NATURE 301, 302 (1984); *see also* SUBUNIT ON CHURCH AND SOCIETY, WORLD COUNCIL OF CHURCHES, BIOTECHNOLOGY: ITS CHALLENGES TO THE CHURCHES AND THE WORLD (1989); H.

ers and organizations.[61] The main arguments against human germ-line therapy are as follows:

1. It is too risky.
2. It is unnecessary.
3. It is wrong.

However, others, including a number of distinguished moral philosophers and some theologians, have argued that the time may come when germ-line therapy is permissible, even highly desirable.[62] Some people believe that time is fast approaching.

A. *Is Germ-Line Therapy Too Risky?*

At the moment it is generally acknowledged that human germ-line therapy is too risky. Researchers cannot, at present, control precisely where new genes are inserted.[63] This raises the not insignificant danger that the inserted gene might damage an existing gene, which could lead to diseases, including cancers. We can note, in passing, that the existence, despite these problems, of germ-line therapy (perhaps better referred to as "germ-line manipulation") in animals (i.e., non-human animals) illustrates the distinction between what is generally deemed acceptable for animals and for humans. Such germ-line manipulation is being used increasingly in agriculture and in medicine.[64]

However, although human germ-line therapy may currently be too risky, it is difficult to imagine that this will continue to be the case indefinitely. It seems extremely likely that scientists will

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Jochemsen, *Medical Genetics: Its Presuppositions, Possibilities and Problems*, 8 ETHICS & MED. 18 (1992).

61. *See, e.g.*, BRITISH MEDICAL ASSOCIATION, OUR GENETIC FUTURE: THE SCIENCE AND ETHICS OF GENETIC TECHNOLOGY (1992); DAVID SUZUKI & PETER KNUDTSON, GENETHICS: THE CLASH BETWEEN THE NEW GENETICS AND HUMAN VALUES (1989); *see also* GROUP OF ADVISORS ON THE ETHICAL IMPLICATIONS OF BIOTECHNOLOGY, EUROPEAN COMMISSION, 1994 REPORT (1996). A number of feminist authors, in particular, have been extremely suspicious about the genetic engineering of humans, suspecting that women are being used as guinea pigs or to produce "perfect babies." *See* ROBYN ROWLAND, LIVING LABORATORIES: WOMEN AND REPRODUCTIVE TECHNOLOGY (1992); PATRICIA SPALLONE, GENERATION GAMES: GENETIC ENGINEERING AND THE FUTURE FOR OUR LIVES (1992).

62. *See generally* CELIA DEANE-DRUMMOND, THEOLOGY AND BIOTECHNOLOGY (1997); JONATHAN GLOVER, WHAT SORT OF PEOPLE SHOULD THERE BE? (1984); JOHN HARRIS, WONDERWOMAN AND SUPERMAN: THE ETHICS OF HUMAN BIOTECHNOLOGY (1992); TED PETERS, PLAYING GOD: GENETIC DETERMINISM AND HUMAN FREEDOM (1997); Mary Warnock, *Ethical Challenges in Embryo Manipulation*, 304 BRITISH MED. J. 1045 (1992).

63. *See generally* CLOTHIER COMMITTEE, *supra* note 54.

64. *See* REISS, *supra* note 3, at 325-30.

develop methods of targeting the insertion of new genes with sufficient precision to avoid the problems that presently attend such procedures. Nor need these new methods require much, possibly any, experimentation on human embryos. A great deal, perhaps all, of the information could be obtained through the genetic engineering of farm animals.

Further, we should realize that although germ-line therapy is typically assumed to be irreversible, it is more likely, if we ever get to the point where its use is routine, that it will normally be reversible. There is no reason to suppose that if something went wrong with the results of germ-line therapy, this wrong would necessarily be visited on a person's descendants in perpetuity. The same techniques that would permit targeted germ-line therapy should permit its reversal.

B. *Is Germ-Line Therapy Unnecessary?*

It is no easy matter to demonstrate that something is "necessary." Value judgments are involved, so that there may be genuine controversy about whether something is needed. Is the motor car necessary? Or elephants? Or free trade? It is likely that most improvements that might result from germ-line therapy could also be effected by somatic gene therapy or conventional medicine. Cystic fibrosis and diabetes are cases in point. However, it may prove to be the case that germ-line therapy allows such conditions to be treated better. It is possible that germ-line therapy might be able to produce certain benefits that could not be realized by any other technique. No doubt the human race would be able to get on without germ-line therapy, and one may question whether it would do much to increase the sum of human happiness. Nevertheless, at some point it may convincingly be argued that germ-line therapy is necessary for some individuals.

C. *Is Germ-Line Therapy Wrong?*

Making the assumption, then, that one day germ-line therapy will both be relatively safe and deemed necessary, in the sense that it can bring benefits that other approaches cannot, is it right or is it wrong?

It is sometimes argued that germ-line therapy will decrease the amount of genetic variation among people and that this is not a good thing, since evolution needs genetic variation.[65] There are several things that are dubious about this objection.

65. *See generally* SUZUKI & KNUDTSON, *supra* note 61.

First, empirically, it is difficult to imagine in the foreseeable future that germ-line therapy will significantly decrease the amount of useful human variation among people. Second, it is possible that germ-line therapy may one day lead to even more genetic variation—as some parents opt for certain genes in their children and other parents for other genes. Third, the argument that evolution needs genetic variation is difficult to sustain faced with someone suffering from a disease that is largely the result of a genetic mutation. The argument relies on possible, very distant advantages for groups of people being sufficient to override the more immediate, clear disadvantages for individuals.

Then some people have expressed the fear that germ-line therapy might be used by dictators to produce only certain types of people. Perhaps the major problem with this objection is that it assumes too much of genetic engineering. As I argued in the context of somatic gene therapy, it is easy to overstate the extent to which humans are controlled by their genes. Dictators have had, have, and will have far more effective ways of controlling people.

A more likely problem is that germ-line therapy will be permitted before people have grown sufficiently accustomed to the idea. The pace of technological change is so fast nowadays that some people end up feeling bewildered by new possibilities. It is worth recalling that people in many countries have grown comfortable with such practices as organ transplants and *in vitro* fertilization, though such procedures gave rise in the aftermath of their initial development to considerable ethical debate (not all of which, of course, has died away—in Japan transplants remain unacceptable, as *in vitro* fertilization is to many Roman Catholics). Similarly, perhaps human germ-line therapy will become broadly acceptable. The theologian, Ian Barbour, has argued that it is important that sufficient time is allowed before germ-line therapy on humans is permitted, both to ascertain, so far as is possible, that the procedure is safe and so that people may feel comfortable with the idea:

> [I] would approve germ-line therapy only under three conditions. First, extensive studies of human *somatic-cell* therapies similar to the proposed germ-line therapy must have been conducted over a period of many years to acquire data on the indirect effects of the genetic changes. Secondly, the effects of similar germ-line therapy in *animals* must have been followed over a period of several generations to ensure the reliability and long-term safety of the techniques used. Third, widespread *public approval* must have been secured, since the therapy will affect unborn

> generations who cannot themselves give informed consent to treatment.[66]

A frequently expressed worry about germ-line therapy is the extent to which future generations will be affected. Again, it is possible that this fear may be an exaggerated one. As we have said, we can overestimate the importance of our genetic make-up. Then there is the point that people already have and will continue to have a tremendous influence over future generations through everything from child-rearing patterns and family planning to books and pollution. The philosophers Robert Nozick,[67] Jonathan Glover,[68] and John Harris[69] have been quite bullish about germ-line therapy. Indeed, Nozick, back in 1974, introduced the notion of a 'genetic supermarket' at which parents, rather than the state, could choose the genetic make-up of their children. Harris has even argued that we may have a duty to carry out germ-line therapy:

> We must not act positively so as to cause harm to those who come after us, but we must also not fail to remove dangers which, if left in place, will cause harm to future people. Thought of in this light, there is a clear dilemma about genetic engineering. On the one hand we must not make changes to the genetic structure of persons which will adversely affect their descendants. On the other hand we must not fail to remove genetic damage which we could remove and which, if left in place, will cause harm to future people.[70]

There remains the worry, though, born of long experience of slippery slopes, that the road to hell is paved with good intentions. Despite the difficulties, which I reviewed earlier, of distinguishing in all cases genetic engineering to correct faults (such as cystic fibrosis, hemophilia, or cancers) from genetic engineering to enhance traits (such as intelligence, creativity, athletic prowess, or musical ability), the best way forward may be to ban germ-line therapy intended only to enhance traits, at least until many years of informed debate have taken place.

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66. IAN G. BARBOUR, 2 ETHICS IN AN AGE OF TECHNOLOGY: THE GIFFORD LECTURES 1989-91 197 (1992).

67. *See* ROBERT NOZICK, ANARCHY, STATE, AND UTOPIA (1974).

68. *See* GLOVER, *supra* note 62.

69. *See* HARRIS, *supra* note 62; *see also* John Harris, *Biotechnology, Friend or Foe? Ethics and Controls, in* ETHICS AND BIOTECHNOLOGY 216 (Anthony Dyson & John Harris eds., 1994).

70. HARRIS, *supra* note 62, at 178.

The idea that it is useful to distinguish between genetic engineering to treat disease and genetic engineering to enhance traits appeals to some theologians who have argued that genetic engineering to treat disease may be seen as part of the redemptive activity of humans.[71] At the same time, it is worth noting the words of J. Robert Nelson, senior research fellow of The Institute of Religion, Texas Medical Center and adjunct professor of medical ethics at Baylor College of Medicine: "The prospect of overcoming and even eliminating from the germ-line certain types of human suffering is, like all other eschatologies, both appealing and frightening."[72]

John Habgood, the former Archbishop of York, has cautioned against using genetic engineering to improve people. In a talk given in 1995 he concluded:

> So, six rules in a sentence. First, human beings are more than their genes. Genes are only a set of instructions. We are more than a set of instructions. Second rule: remember the valuable diversity of human nature. Third rule: look for justice in the dealings of human beings with one another and for fairness in the use of resources. Fourth rule: respect privacy and autonomy. Fifth rule: accept the presumption that diseases should be cured when it is possible to do so. And sixth rule: be very suspicious about improving human nature; and be even more suspicious of those who think they know what improvements ought to be made.[73]

Nor is it only religious leaders who have warned of the dangers of presuming to improve human nature or enhance human capabilities. Jonathan Glover quotes the philosopher John Mackie who once argued, against Glover's optimism about germline therapy, that "if the Victorians had been able to use genetic engineering, they would have aimed to make us more pious and patriotic."[74]

A related difficulty is that if we ever did succeed, through either somatic cell or germ-line therapy, in enhancing such traits as intelligence, memory, or altruism, there might be unforeseen consequences. There exists a genetically engineered strain of

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71. *See generally* RONALD COLE-TURNER, THE NEW GENESIS: THEOLOGY AND THE GENETIC REVOLUTION (1993).

72. NELSON, *supra* note 59, at 164.

73. John Habgood, Heslington Lecture at the University of New York (Feb. 1, 1995) (Transcript on file with the *Notre Dame Journal of Law, Ethics & Public Policy*).

74. GLOVER, *supra* note 62, at 149.

the fruit fly, *Drosophila* which learns ten times faster than the normal strain.[75] At first sight the application of this technology to humans sounds marvelous. Imagine learning ten times faster; think of all the benefits it could bring. However, there may be costs. Improved learning implies improved memory and if you have a far superior memory you will forget far less. Most of us have experienced unpleasant happenings which we are only too grateful to forget. Further, there is some anecdotal evidence to suggest that the handful of people who have total recall or perfect photographic memories find life difficult. For a start, they don't always find it easy to know what day, month, or even year it is. If you have a perfect memory, events a year ago may be almost as fresh in your mind as events five minutes ago. This can lead to confusion and can make social relationships difficult.

Finally, it might be the case that genetic engineering would require parents to choose which traits they would like enhanced in their children. It may, for example, prove impossible simultaneously to enhance a child's ability to learn mathematics, paint, show great empathy, and play a musical instrument. It can be argued that genetic engineering to enhance human traits diminishes the autonomy of the person concerned—*i.e.*, the genetically engineered child that results. On a more practical level, one can imagine arguments between genetically engineered children and their parents, with great unhappiness sometimes resulting: "We didn't pay for you to be musically gifted just to have you spend all your time playing baseball" or "We didn't pay for you to be an outstanding baseball player just to have you spend all your time in a rock band."

Nevertheless, suppose that one day it really does become possible safely to improve everyone's IQ by some twenty to forty points through germ-line modification. Imagine further that this procedure especially benefits those who would otherwise have an IQ of below one hundred (in other words, it decreases the variance in IQ scores rather than increasing it) and that the procedure can be carried out much more effectively and cheaply than via other routes (e.g. somatic gene modification, psychosurgery, or extra education). My own belief is that it would prove difficult to argue that such a procedure should be made illegal. It is more likely that we would be discussing whether it should (like education in general) be mandatory or (like school education) be optional.

75. Peter Aldhous, *Fruit Flies Achieve Total Recall*, NEW SCIENTIST, Apr. 29, 1995, at 18.

VII. MAKING ETHICAL DECISIONS

It may seem somewhat surprising only now in this article to have a section on "Making Ethical Decisions," but there is a logic to this. While the traditional approach in the West to making ethical decisions historically has been to argue from general principles to particular cases, ever since Carol Gilligan's classic book, *In a Different Voice*,[76] the value of arguing rather from particular cases to general principles has increasingly been recognized.[77]

One reason for such an approach is that, without exaggerating too much, it can be asserted that Western moral philosophy is currently, and has been for over a hundred years, in a state of intellectual crisis.[78] The most obvious manifestation of this crisis is the fact that there still exists no accepted framework within which ethical decisions can be made. Quite the opposite: there exist a number of competing and mutually incompatible frameworks. The best known of these are the consequentialist and the non-consequentialist ones. Consequentialists hold that, to decide whether an action would be right or wrong, it is sufficient to look at what its consequences would be, whereas non-consequentialists hold that this is inadequate.[79]

My own view is that whether or not consequentialism in general is sufficient as an ethical system, it is difficult to sustain non-consequentialist objections to the genetic engineering of humans. Suppose, for example, person A argues that it is intrinsically wrong (i.e., wrong whatever the consequences) to carry out germ-line modification on humans. That means that even if it could be shown that the relief of person B's suffering or the advancement of person C's autonomy or the promotion of justice between persons D, E, . . . Z could only be achieved through

76. CAROL GILLIGAN, IN A DIFFERENT VOICE: PSYCHOLOGICAL THEORY AND WOMEN'S DEVELOPMENT (1982).

77. *See generally* Jean Grimshaw, *The Idea of a Female Ethic, in* A COMPANION TO ETHICS 491, 494-95 (Peter Singer ed., 1991).

78. *See, e.g.*, ANNE MACLEAN, THE ELIMINATION OF MORALITY: REFLECTIONS ON UTILITARIANISM AND BIOETHICS (1993); BERNARD WILLIAMS, ETHICS AND THE LIMITS OF PHILOSOPHY (1985).

79. Put more formally "Opponents of consequentialism see the relation between values and agents as a non-instrumental one: agents are required or at least allowed to let their actions exemplify a designated value, even if this makes for a lesser realization of the value overall." Philip Petit, *Consequentialism, in* A COMPANION TO ETHICS 230, 231 (Peter Singer ed. 1991). The question is not whether we need to take consequences into account when making ethical decisions but whether that is all that we need to do.

human germ-line modification, person A would maintain that such courses of action would be wrong.[80]

If it is indeed the case that arguments about the genetic engineering of humans should be conducted solely within a consequentialist framework, the ethical issues are considerably simplified. Deciding whether genetic engineering is right or wrong now reduces to a series of detailed, in-depth studies of particular cases. Ethicists still have a role to play, but of perhaps greater importance are scientists and others who know about risks and safety, while sociologists, psychologists, policy makers, and politicians who know about people's reactions and public opinions also have a significant role. For remember, to a consequentialist there are no moral absolutes. What is right is simply determined by the overall consequences (typically the net difference between benefits and harms) that flow from a course of action.

VIII. THE VOICE OF THEOLOGY

Some readers may be disappointed at so late an introduction into this article of a section specifically addressing theological concerns. Others, though, may wonder what the contribution of theology to the debate about genetic engineering can be given that the world's great religions have nothing explicit to say on the subject. Although this latter point has a certain validity, the world's great religions do have a great deal to say about such issues as creation, our use of the natural world and human responsibility, all of which clearly connect with genetic engineering. In addition, it is worth noting that even in countries, such as the United Kingdom, where only some ten percent of people regularly worship, surveys indicate that a significant number of people object to genetic engineering on the grounds that it is against God's will or contrary to their religious beliefs.[81] So theo-

80. The question as to whether person A should campaign for laws to be passed banning germ-line modification is a slightly different one. It is possible for a person to believe that a course of action is always wrong yet not to campaign that it should be made illegal. For example, many religious believers—though not all!—would today hold that failing to worship God is wrong without wishing to make such worship a legal requirement.

81. A 1992 study of 1228 telephone interviews in the United States showed that the more important a person's religion was to them, the more likely they were to believe that genetic engineering was wrong. *See* T.J. HOBAN & P.A. KENDALL, CONSUMER ATTITUDES ABOUT THE USE OF BIOTECHNOLOGY IN AGRICULTURE AND FOOD PRODUCTION (1992). The same survey showed that while the most common reason for opposing biotechnology involved concerns that it would "threaten the balance of nature," a significant proportion mentioned that biotechnology was "not natural," somehow "against God's will" or "contrary to [their] religious beliefs." *Id.* It is difficult to quantify the

logical concerns about genetic engineering matter because many people have them.

Genetic engineering is increasingly being examined from a theological perspective, though most of what has been written is the product of Christian writers.[82] Three main approaches can be identified: rejection, hesitancy, and acceptance with caveats.

Some authors reject genetic engineering on the grounds that genetic engineering entails humans having too much power over animals. Andrew Linzey, for example, considers genetic engineering to be a form of slavery:

> [G]enetic engineering represents the concretisation of the *absolute* claim that animals belong to us and exist for us. We have always used animals, of course, either for food, fashion or sport. It is not new that we are now using animals for farming, even in especially cruel ways. *What is new is that we are now employing the technological means of absolutely subjugating the nature of animals so that they become totally and completely human property.*[83]

One obvious problem with this argument is that certain animals, not to mention plants, have been considered human property in practically every society since time immemorial. Farm animals and pets, in particular, are always owned by people.

Another possible reason for rejecting genetic engineering is that it involves too exploitative a view not just of animals but of all of nature. Martin Heidegger argued that in technology we make objects according to some blueprint that we determine.[84]

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importance of religious beliefs to such attitudes, but similar studies in New Zealand, Japan, and Europe also show that religious beliefs are among the most widely cited reasons why some people consider genetic engineering to be unacceptable. *See* P. K. COUCHMAN & K. FINK-JENSEN, PUBLIC ATTITUDES TO GENETIC ENGINEERING IN NEW ZEALAND (1990); Bernard Dixon, *Biotechnology a Plus According to European Poll*, 9 BIO/TECH. 16 (1991); Daryl R.J. Macer, *Public Acceptance of Human Gene Therapy and Perceptions of Human Genetic Manipulation*, 3 HUMAN GENE THERAPY 511 (1992); *European Commission Directorate—General XII for Science, Research and Development*, BIOTECHNOLOGY: EUROPEAN OPINIONS ON MODERN BIOTECHNOLOGY - EUROBAROMETER 46.1 (1997).

82. *See* COLE-TURNER, *supra* note 71; DEANE-DRUMMOND, *supra* note 62; NELSON, *supra* note 59; PETERS, *supra* note 62; REISS & STRAUGHAN, *supra* note 6; Anthony Dyson, *Genetic Engineering in Theology and Theological Ethics*, *in* ETHICS AND BIOTECHNOLOGY 259 (Anthony Dyson & John Harris eds., 1994).

83. Andrew Linzey, *Human and Animal Slavery: A Theological Critique of Genetic Engineering*, *in* THE BIO-REVOLUTION: CORNUCOPIA OR PANDORA'S BOX 175, 180 (Peter Wheale & Ruth McNally eds., 1990). *See also* ANDREW LINZEY, ANIMAL THEOLOGY (1994); Hugh Montefiore, *Rights In Animals*, CHURCH TIMES, Feb. 19, 1993.

84. *See generally* MARTIN HEIDEGGER, THE QUESTION CONCERNING TECHNOLOGY AND OTHER ESSAYS (William Lovitt trans., 1977).

We design things to satisfy our purposes rather than allow our purposes to be affected by, and find creative expression through, the qualities of the objects themselves. Heidegger's point is particularly apposite when applied to genetically engineered organisms.

The most frequent response by religious writers to the issue of genetic engineering is one of caution or hesitancy. In particular, some people may hesitate about the movement of genes between humans and other species, fearing that this somehow diminishes the distinctiveness of being human. For example, the notion that humans are made *imago Dei* may cause some with a Christian faith to feel uncomfortable about a technology that apparently threatens to blur the dividing line between humans and the rest of the created order.[85] Of course, others may feel differently, perhaps believing that all of creation is, in a way, *imago Dei*; for how can that which is created do other than reflect its creator, sustainer, and redeemer?

Finally, though this category overlaps with the previous one, there are religious writers who accept genetic engineering, though typically with certain specific caveats. Phil Challis, arguing against Andrew Linzey's rejection of genetic engineering considered above, writes

> We are co-creators with God, "fearfully and wonderfully made" (Ps 139:14). With our finite freedom we are called by Him to act responsibly as we continue the process of genetic manipulation of domestic organisms. A theology that emphasizes embodiment rather than body-spirit dichotomy, that emphasizes becoming rather than immutability as an essential part of God's nature, that emphasizes relationship within the web rather than domination from outside the system, such a Christian theology may provide a critical framework that can realistically embrace the potential of genetic engineering for good.[86]

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85. *See* 1 *Corinthians* 15:39 (Revised Standard Version) ("For not all flesh is alike, but there is one kind for men, another for animals, another for birds, and another for fish.").

86. PHIL CHALLIS, GENETIC ENGINEERING AND ITS APPLICATIONS: SOME THEOLOGICAL AND ETHICAL REFLECTIONS 39-40 (1992). Celia Deane-Drummond argues that "[a] theological approach encourages those involved to see the wider social and religious consequences of these decisions. It does not necessarily ban all genetic engineering, but seeks to transform it so that it more clearly represents a fully human enterprise." Celia Dean-Drummond, *Reshaping Our Environment: Implications of the New Biotechnology*, 5 THEOLOGY IN GREEN 19, 26 (1995).

Ronald Cole-Turner has explored the implications of a distinction between humans as co-creators with God—a concept which, he feels, contains a number of difficulties—and humans as participants, through genetic engineering, in redemption.[87] Here redemption is being used in the sense of "restoration." The idea is that genetic engineering can help to overcome genetic defects caused by harmful mutations. In this way genetic engineering can help to restore creation to a fuller, richer existence and can, Cole-Turner maintains, play an important role without encroaching on the scope of divine activity.

It can perhaps be argued, in this vein, that humans may have a theological responsibility, even a duty, to use genetic engineering to root out imperfections in the natural world, including those found in humans. Viewed in this light, genetic engineering can be seen as a tool with the potential to eliminate harmful genetic mutations, reduce suffering, and restore creation to its full glory.

IX. SEEKING CONSENSUS

We live in an increasingly pluralistic society. Within all Western countries there is no longer a single shared set of moral values. Even the various religions disagree on ethical matters and many people no longer accept any religious teaching.

Nevertheless, there is still great value in taking seriously the various traditions—religious and otherwise—that have given rise to ethical conclusions. People do not live their lives in isolation: they grow up within particular moral traditions. Even if we end up departing somewhat from the values we received from our families and those around us as we grew up, none of us derives our moral beliefs from first principles, *ex nihilo* as it were. In the particular case of moral questions concerning biotechnology, a tradition of ethical reasoning is already beginning to accumulate.[88] Many countries have official committees or other bodies looking into the ethical issues that surround at least some instances of biotechnology.[89] The tradition surrounding ethical reasoning in this field is nothing like as long established as, for example, the traditions surrounding such questions as abortion,

87. *See generally* COLE-TURNER, *supra* note 71.

88. *See generally* Michael J. Reiss, *Ethical Issues*, *in* 224 CONFERENCE OF ROYAL SOCIETY OF MEDICINE: GENETIC ENGINEERING IN FOOD PRODUCTUCTION 165 (Lord Soulsby of Swaffham Prior ed., 1997).

89. *See generally* BIOTECHNOLOGY INDUSTRY ORGANIZATION, STATEMENT OF PRINCIPLES (not dated); EUROPABIO, EUROPABIO'S CORE ETHICAL VALUES (1998).

euthanasia, war, and trade protectionism. Nevertheless, there is the beginning of such a tradition and similar questions are being debated in many countries across the globe.[90]

Given, then, the difficulties in relying solely on either reason or any one particular ethical tradition, we are forced to consider the approach of consensus.[91] It is true that consensus does not solve everything. After all, what does one do when consensus cannot be arrived at? Nor can one be certain that consensus always arrives at the right answer—a consensus once existed that women should not have the vote. Nonetheless, there are good reasons both in principle and in practice in searching for consensus. Such a consensus should be based on reason and democratic debate and take into account long established practices of ethical reasoning. At the same time, it should be open to criticism and refutation and the possibility of change. Finally, consensus should not be equated with majority voting. Consideration needs to be given to the interests of minorities, particularly if they are especially affected by the outcomes, and to those—such as young children, the mentally infirm and non-humans—unable to participate in the decision-making process.

X. CONCLUSION

Somatic gene therapy for a number of medical conditions, such as cystic fibrosis, is beginning to offer the realistic possibility of improving physical health, relieving stress, worry, and other psychological problems, and reducing the number of abortions. Further, it is not significantly different, in principle, from other medical treatments. Those who accept conventional medicine—the overwhelming majority of people—should have no qualms about accepting the benefits of somatic gene therapy provided it is shown to be safe and efficacious.

However, the likely benefits of somatic gene therapy should not be overstated. Most human disease will not be eliminated through its adoption. In time somatic gene therapy is likely to prove to be just one of a number of important therapeutic approaches used in the prevention and treatment of human disease.

At present, germ-line therapy is unsafe. In time, though, this may change. In my opinion the ethical arguments in favor of

90. *See generally* EUROPABIO, *supra* note 89.

91. *See generally id. See also* JONATHAN D. MORINO, DECIDING TOGETHER: BIOETHICS AND MORAL CONSENSUS (1995); Lady Warnock, *Religion, Morality and Human Reproductive Technology*, *in* 2 FARMINGTON PAPERS PHILOSOPHY OF RELIGION (1998).

a total, unconditional, and permanent ban on germ-line therapy are not overwhelming. There may prove to be strong arguments in favor of the careful use of germ-line therapy to alleviate suffering in certain circumstances.

For the foreseeable future it is probably best to outlaw the use of either somatic or germ-line modification to enhance human traits. In time such applications of genetic engineering may be practicable, safe, and desirable. However, not everyone will agree on what changes, if any, should be made. In such circumstances it would be better to err on the side of caution.