
Chapter – II

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Gene Therapy in the Offing

In a process almost as old as the earth, a huge panoply of organisms has evolved. The process has been one of chance and selection. It appears that we have now come to the end of that familiar pathway. Genetics has unlocked the code book of life, and the long-hidden strategies of evolution are revealing themselves. We now possess the ability to manipulate genes, and we can direct the future course of evolution. Mutation and natural selection will continue, of course. But henceforth, the old ways of evolution will be dwarfed by the role of purposeful human intelligence. In the hands of genetic engineer, life forms could become extraordinary Tinkertoys.

To view genetic engineering as merely another technological development may make sense for those who invest in its commercial exploitation. But such a view is myopic for anyone concerned with the future of humanity. Scientific knowledge of how genes work will empower human beings to cure and prevent diseases. It may also let us shape some of the most important biological characteristics of the human beings that we choose to bring into existence. No one can predict at this juncture the limits of our future powers to shape human lives. Whatever the limits of our technical capabilities turn out to be, coping with these new powers will tax our wisdom to the utmost. Reflection on scenarios like this makes us worried. We worry, e.g., whether we will suffer the consequences of partial knowledge, overestimating our power to predict and control the causal chains we initiate through the application of our newfound knowledge. We also worry about our current values. Even if we were more assured that our

technical control would be complete, we would continue to wonder whether we would be able to distinguish between what we can do and what we ought to do. The questions that will continue to haunt us: Do we have ethical measures to use our genetic powers wisely and humanely? Do existing ethical theories, concepts, and principles provide us the materials for constructing more adequate instruments for our moral navigation? In the face of these doubts about whether our values will keep pace with our powers, there are many forebodings about the dangers of 'playing God' whenever there are new genetic discoveries or technical breakthroughs. Gene therapy is one of such areas of debate that has caused much concern and is not constant but in a flux. It needs to be constantly reviewed in the light of the new advancement that this rapidly expanding science makes. My present effort is a modest venture in this direction.

What is gene therapy?

Three important constituents of genetic science are genetic screening, genetic counseling and gene therapy. Through genetic screening when it is detected that a gene is deleterious the genetic counselor may advise the carrier of the gene to go for gene therapy. Therapy, by definition, is the treatment of an individual. Therefore, the term gene therapy is used to mean any procedure that has as its purpose the prevention, reduction, or cure of a genetic disease.

The prospect of gene therapy emerged in 1928 when Griffith transferred a species of bacteria from non-virulent to virulent. He brought about a permanent genetic change in these bacterial cells. Since then methods for gene exchanges have been intensely investigated. Knowledge gained from these studies prepared the way for investigations in the transfer of DNA within many species of plants

and animals, both in vitro and in vivo. In 1980, the first attempt, using recDNA¹, was made to correct beta thalassemia in two defective women. A few viral-mediated gene transfers in mouse bone marrow have proved successful and were the model by which investigators performed the first sanctioned human gene transfer in 1989. Although there are three ways in which gene therapy might occur—gene insertion, gene repair, or gene surgery—initially only gene insertion is being attempted. Gene repair and gene surgery are too complex at the moment.

Genetic diseases that may be treatable can be separated into three age-related groups. Group-I includes embryos and foetuses that carry defective genes. Group-II therapy involves perinatal or childhood-defective phenotypes or carriers of late-onset genetic defects. Group-III involves defective adolescent and adult phenotypes and carriers of late-onset genetic defects. Currently, there are relatively few genetic diseases in any group having symptoms that can be completely normalized using medical therapies. Even in those cases wherein a patient is normalized by medical therapy, he/ she is not 'cured'. The person in question carries the defective gene. The only hope of complete cure is gene therapy.

In order to understand the ethical issues centering round gene therapy, we need to mention one important distinction between two broad categories of gene therapy: somatic gene therapy and germ-line gene therapy. Somatic gene therapy affects the body cells of an individual and hence does not affect his/ her descendants. Germ-line therapy, on the other hand, affects the reproductive cells thereby

1. Rec DNA means recombinant DNA, i.e., DNA molecules that have been assembled by splicing together fragments from the same or different species with the use of restriction enzymes.

having an impact on that individual's children directly and ultimately on the gene pool of the species.

The possibility of genetic engineering, i.e., not to correct defects, but to add desirable characteristics, is not a distant hope. Rational debate of this potential has already begun. It is expected that gene therapy will increase the affected person's life span and improve the quality of his/ her life. In many cases a good diagnosis and discussion of available therapy will at least eliminate the agony that parents undergo while looking for answers to what is it and can it be treated.

Ethical quandary

From the above it appears that the future of gene therapy and the cure of genetic diseases are very promising. In spite of this, like many other issues of genetics, gene therapy has become one of the thorny facets of genetic engineering. Why? Due to various developments in the past we no longer take it for granted that progress in medical and biological research is a good thing. We question the adequacy of society's wisdom in dealing with the explosive increase in biomedical knowledge. Just as we recognise that nuclear energy may be used for constructive as well as for destructive purposes, so also the spectacular finding that DNA is the chemical basis for heredity. It increases man's knowledge of nature so much that it lays on him a tremendous responsibility to use wisely this newly acquired power. What is feared at is that the same basic procedures that may help us to cure one set of illness may also lead to grand-scale manipulation of human behaviour. For instance, the procedures that are now being developed to correct those genetic deficiencies causing severe illness might also be used to breed people of unusual physical strength.

However, do all these concerns demand that we should stop genetic research?

When juxtaposed the two opposite sides of this new technique we find ourselves in an ethical quandary. On the one hand, it is a technique full of promises, on the other social scientists are concerned of its use apprehending that it may be misused as history gives us umpteen instances of it. The issues that worry us can be summed up thus: Is it safe, is it wise, is it moral? While I was engrossed in thinking about the ethical predicaments that we face with the development of this new science and was thinking how the promises of this science can be brought to terms with the ethical concerns, I came across a letter of an agonised father that appeared in the New York Times. The letter was written in response to a column in the same paper written on September 5 by an eminent sociologist, A. Etzioni. Mr. Etzioni's point was that before we apply the newfound knowledge in genetics, we must have clearer idea of the moral and social choices involved in the biological revolution and the mechanisms by which science can be guided without being stifled. Let us quote some relevant portions of that letter: "Being a father of two sons who are infirm with muscular dystrophy, I found the ... column by A. Etzioni on genetic manipulation repulsive and totally devoid of sense. I see my two sons withering and weakening as the days go by. The future holds nothing for them but the inevitable wheelchair at nine and certain slow death by nineteen. The only scant hope for their survival is the effort made by medical research to break the genetic code and be able to reverse the disease. Comes Mr. Etzioni and advocates a go-slow attitude toward accomplishing this scientific feat. Until he and other professors of sociology make up their mind, 'What superman will the national task force order? Blond or brown, white or black?' To satisfy

Mr. Etzioni's intellectual imagination, I shall answer him: Just revive dying children first, produce superman later It would be a sheer tragedy to waste [money] ... on idle sociology professors to explore options created in their imagination."² I was greatly moved by the personal agony of the sons and their father. I felt that nothing should be done to delay service to them. But gradually it dawned on me that no rational decision can be made if the agony of an individual—however moving and tragic—is its basis, and the greater sufferings of the greater number—which are less immediate and less dramatic—are ignored. True, it is the essence of our libertarian tradition not to sacrifice a person for the multitude. But one cannot disregard, either, that the multitudes are made out of nothing but of many individuals. Above all, the quest must be for solutions that allow those afflicted to be served while protecting the rest of us, rather than seeking either to block the progress of genetics or to embrace its entire offspring indiscriminately. It is this feeling that will be the leitmotif of the following sections.

Arguments for and against Gene therapy

As the ethics of gene therapy was hotly discussed during the last quarter of the twentieth century, the UK government set up a committee (popularly known as Clothier Committee) to consider the ethical aspects of it. This committee identified the following two principles as governing its deliberations:

- the obligation inherent in human nature to enquire, to study, to pursue and apply research by ethical means; and

2. *The New York Times*, September 29, 1970.

o in the sometimes-inescapable tensions between the pursuit of knowledge and the protection of patients' interests, the latter must prevail.³

The fact that the first principle speaks of the obligation to pursue research rather than to relieve suffering may be explained by the Committee's view that gene therapy should at least initially be regarded as research involving human subjects rather than as therapy, and should accordingly be subject to the requirements for all ethically acceptable research. To describe gene therapy as the pursuit of knowledge rather than the research for a cure rules out the possibility of classifying gene therapy as innovative treatment. On many occasion Clothier report has been criticized for its insufficient attention to curative goals.

In spite of the report of the Clothier, we know that gene therapy has a specific aim, i.e., curative goals, in medical science. Genetic disorders cause suffering. Treatment other than gene therapy can at most alleviate symptoms. Gene therapy offers the prospect of a cure.

A close scrutiny of arguments given against gene therapy makes it plain that gene therapy has proved controversial because it involves actual alteration of an individual at the genetic level. An analogy is sometimes drawn, however, between gene therapy and organ transplants—receiving a foreign gene is, for example, analogous to receiving a foreign kidney. Thus, it is argued that it (i.e., gene therapy) should be regarded in the same way as other forms of medical treatment. This argument may, however, hold good for somatic therapy, but not for germ-line therapy. Thinkers see a moral difference

3. Clothier C.: *Report of the Committee on the Ethics of Gene Therapy*, 1992. London: HMSO.

between these two, and say, as we shall see later, that while somatic therapy is morally acceptable, germ-line therapy is not.

There was almost total concurrence, even before the clinical trials began, that somatic gene therapy was not basically new in the kinds of ethical issues it raises and by and large they could be dealt with in the same way as any innovative therapeutic treatment (e.g., by establishing ethics committees, reviewing the protection of patients' rights and safety and so on). This is not to say that somatic gene therapy poses no ethical problems. But these problems, however important and often troubling they may be, do not differ in kind from those that are inherent in many clinical trials of new and unproved treatments, with perhaps the additional dilemmas caused by the hype and false hopes that have surrounded some early gene therapy trials.

On the other hand, most observers agree that germ-line gene therapy poses quite another set of questions. To contemplate gene transfer into the human germ-line was to place the issue squarely into the realm of trans-generational therapy. It has the consequence that in such therapy the whole genome of certain future people would be envisioned as the object of willful and targeted modification. Hence there is a developing consensus that whereas somatic therapy is morally acceptable, germ-line therapy is not, at least for the foreseeable future.

Now if it can be shown that the target that we achieve through germ-line gene therapy can also be achieved by some other means then the entire controversy surrounding the germ-line gene therapy can be easily obviated. One main aim of germ-line gene therapy is the absence of children with genetic disorders. In order to achieve this aim some couple might take recourse to what the British geneticist Marcus

Pembrey has called a 'winning combination'⁴ of genes without engaging in germ-line gene therapy. In vitro fertilization and embryo selection offer a way to do this, by testing the embryos and selecting the best to return to the womb. But what counts as a 'winning combination' is a matter of dispute, as is shown by current controversies concerning whether deafness is a genetic disadvantage or a cultural difference.⁵ Anyway, Pembrey himself has admitted that there are a small number of couples who could not have recourse to the 'winning combination' and for them germ-line gene therapy might provide the only chance of producing a child of their own without genetic disease: e.g., in the case of mitochondrial disease, where all of a woman's offspring are at risk.

Thus it has become clear that there are a small number of cases where germ-line gene therapy becomes necessary primarily because parents may prefer to have gene therapy on their own embryos. This may be perceived as desire for having a child of their own, in other words, genetically related to both parents. It may be argued that in germ-line gene therapy they would be accepting external genetic material. But what is significant here is the desire of parents to pass genetic material of one or both of them on to the next generation. It is this concern that outweighs the threat of external material in germ-line gene therapy. All the above has established that there is a demand for germ-line gene therapy. The question remains to be discussed is whether, in the light of this, germ-line gene therapy should be practised.

Having established that gene therapy is the only hope in

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4. Pembrey, M.: 'Embryo therapy: is there a clinical need?' in D. R. Bromhans *et al.* (ed.): *Ethics in Reproductive Medicine*, London, Springer-Verlag, 1992.
 5. Grundfast K. and Rosen J., 'Ethical and cultural considerations in research on hereditary deafness' in *Molecular Biology and Genetics*, 1992. pp. 973-7.

certain cases of disease, now let us turn to a closer look at the arguments for and against germ-line intervention. Eric T. Juengst summarizes the following arguments given in favour of germ-line modification for the purposes of therapy:

— Medical utility: it offers a true cure for many genetic illnesses, not simply a treatment of symptoms.

— Medical necessity: such therapy is the only effective way to address some diseases.

— Prophylactic efficiency: by preventing the transmission of disease-causing genes, the risks and costs of therapy for future generations are reduced.

— Respects of parental autonomy: doctors are obliged to respond to the health needs of prospective parents who are at risk for transmitting serious genetic diseases.

— Scientific freedom: prohibiting gene therapy research restricts the intellectual freedom of researchers.⁶

Supporters of gene therapy research concede that it involves experimenting with human embryos, but argue that this is necessary to benefit generations in the future. Successful gene therapy will make it possible to save the lives of many infants who would otherwise die, and reduce the need to make difficult decisions about what to do with embryos that have a genetic disease.

Let us now summarize the arguments given against germ-line intervention:

6. Eric T. Juengst, 'Germ-Line Gene Therapy: Back to Basics', *Journal of Medicine and Philosophy*, 16: 6 (December 1991) 589-590.

--- Scientific uncertainty and risks to future generations: The long-term effects of germ-line gene therapy cannot be assessed without clinical follow-up of patients over generations, a difficult if not impractical prospect. It is also apprehended that by removing diseased genes from the genome of future persons, one may unwillingly eliminate the hidden collateral benefits that those genes may also have.

--- Some thinkers oppose germ-line interventions on the ground that it amounts to 'playing God'. They condemn it as arrogant and illegitimate interventions into the natural order. The basic idea, buttressed by recourse to familiar icons such as the Sorcerer's Apprentice, Dr. Faust and Frankenstein, is that man does not have the wisdom and foresight needed to exert the powers of the creator. And if he were indeed wise enough he would abstain from acting above his God-given station in the universe.

Germ-line modification is the start of a slippery slope to enhancement. Once the techniques of gene modification have been developed, they are open to misuse, tempting those in power to alter genes for reasons other than eliminating disease.

--- Consent of future generations is impossible to get. This argument points to the fact that trans-generational gene therapy would amount to non-consented therapy on not-yet-existing people. Persons belonging to the distant future and affected by germ-line gene therapy performed now would be held hostage to what we think is good for them.

--- Allocation of resources: germ-line gene therapy may never be cost effective. A question often asked is the increasing cost of high-tech medical care in general and the price society pays for a

strained health care system. Can we afford such expensive therapy, and who should receive it? And who decides?

— Integrity of genetic patrimony: it is argued that future generations have the right to inherit a genetic endowment that has not been intentionally modified.

Thus it is seen that ethical controversy about gene therapy centres round the germ-line intervention. It is this issue that has proved intractable.

Alexander Mauron opines that most of the debate about germ-line gene therapy stems from two conceptual problems. These are:

i) Germ-line gene therapy on humans is a technology whose concrete empirical outlines can only be guessed at. Ethical evaluation of a technology, which still belongs to a speculative future, is beset with epistemological uncertainties, which raise the more general problem of anticipatory evaluation and regulation of this exotic technology.

ii) It is not clear what sort of germ-line interventions would qualify as 'therapy'. This is an added element of conceptual uncertainty that makes an ethical evaluation difficult.⁷

It is true that a set of anticipations from present knowledge and practices make the topic controversial. Science-fiction scenarios, perhaps, have added more dimensions. And more important it is to notice that rather than the distinction between somatic and germ-line gene therapy, it is the distinction between therapeutic and ameliorative

7. Alexander Mauron: 'Ethical aspects of germ-line gene therapy' in *Genetics in Human Reproduction* ed. by E. Hildt and S. Graumann. Ashgate, 1999, p. 107.

genetic interventions that occupied the centerstage of ethical discussions. To be more precise, for many, gene therapy for healing real diseases is acceptable, but gene therapy that aims at improving human nature by adding novel biological properties not usually found in human persons is eugenic (or immoral by definition) and should not be allowed. In scholarly debate, however, this view has never met with unanimous assent but continued to invite controversy. We find many instances where the conceptual relevance of this distinction (i.e., the distinction between bona fide therapy and enhancement) was challenged or the ethical rejection of germ-line gene therapy and/ or genetic enhancement was questioned.⁸

A little reflection makes it clear that it is not difficult to render a critique of the arguments given (and we have summed up) against germ-line intervention. Although it is true that great caution must be taken, still it is difficult to believe to believe that the dangers call for a lack of vision or a lack of courage. There are many who opine that the theological concept of anthropology emphasises that human creativity be placed in the service of visionary beneficence, and germ-line modification should be considered one possible means oriented towards a beneficent end. For Ted Peters, a thinker in this field, if we understood God's creative activity as giving the world a future and if we understand the human being as a created co-creator, then ethics begins with envisioning a better future. This suggests that we should at minimum keep the door open to improving the human genetic lot and, in an extremely modest way, influencing our evolutionary future. If we can welcome the steps taken to influence (i.e., to expedite) our spiritual evolution (e.g., by Sri Aurobindo) then why should we fear to think about expediting physical evolution using genetic means? The derisive

8. E. g. by Lappe 1991, Wivel and Walters 1993, Agar 1995, Holtung 1997 and so on.

use of the phrase 'playing God' should not deter us from shouldering our responsibility for the future. "To seek a better future is to 'play human' as God intends us to."

The first argument delineated by us against germ-line manipulation is technical. It states that although the motive for modifying germ genes may be the enhancement of human well being for future generations, unexpected deleterious consequences may result. Removal of an unwanted diseased gene may not eliminate the possibility that other gene combinations will be created that will be harmful. Inadvertent damage could result from biologists' inability to predict just how genes or their products interact with one another and with the environment. Therefore it would be argued by the prudent observer that we take a 'wait and see' attitude and that we move cautiously as the technology develops.

But the problem of unexpected consequences is one that confronts all long-term planning, and in itself should not deter research and experimentation guided by a vision of a healthier humanity.

About the argument that by removing disease genes one may unwillingly eliminate the hidden collateral benefits of these genes it may be candidly admitted that many recessive disease genes have been maintained in human populations by selective pressures favouring heterozygotes. There are hypotheses about the heterozygote resistance for a few recessive diseases. But this sort of benefit is only relative. More importantly, it is populational rather than individual and usually reflects the evolutionary past of human conditions. It is contrary to reason to conclude that recessive disease genes should always be preserved for the sake of this hypothetical populational benefit against the interest of actual suffering individuals. In addition, the argument is

invalid for dominant disease-causing mutations, where the hidden benefit is excluded by definition. Mauron calls the intuitive appeal of this argument 'the Panglossian view of the genome'. Just as Voltaire's Dr. Pangloss thought that all evil is a hidden good, similarly it may be argued that we should believe in a kind of pre-established genomic harmony, where disease genes are present for some good reason, otherwise nature would not have put them there. But the nature, that put them there, is just the sum-total of the blind and opportunistic strivings of natural selection, utterly indifferent to the good of human individuals. It is true that anyone who is not opposed to germ-line gene therapy would nevertheless want to see it scrutinised very carefully for its long-term safety. But is it not true that any treatment that irrevocably modifies the biological constitution of future people—and therefore resonates indefinitely into future—can ever pass muster in terms of safety, because some of its possibly deleterious effects would necessarily lie beyond the horizon of every possible prediction.

About the argument that in resorting to germ-line intervention we are tempering with gene pool as these so-called bad genes may have some hidden benefits it may be suggested that we would have to be very confident indeed of a number of things before we might be justified in accepting such a cruel gamble: first, there is indeed a positive side of the defective gene; second, that such a positive side is sufficiently important to be worth preserving at the terrible cost in human suffering that would be required to preserve it; and finally, such positive effects can not be or are not likely to be achievable in any other way. In the absence of such confidence no sane being would think it worth preserving disability and disease on the off chance that some good might come of it at some unspecified and unpredictable point in the future.

Let us now turn to the caution 'Thou shalt not play God' (second argument given against). The acerbic rhetoric, it is sometimes argued, that usually employs the phrase 'playing God' is aimed at inhibiting, if not shutting down, certain forms of scientific research and medical therapy (and mainly germ-line gene therapy). Here the problem arises if the reference of plying God is taken literally. Theologians are not usually enthusiastic about prohibitions on 'playing God'; logically invoking the notions that man is called upon by God to be a cocreator, and not merely a passive and subservient caretaker of the creation. We find expressed evidence that Christian, Jews and Muslim theologians are supporting germ-line gene therapy.⁹ For instance, the Catholic Health Association of America opines that if we can improve human health through germ-line intervention, then it is morally desirable. For it, "Germ-line intervention is potentially the only means of treating genetic diseases that do their damage early in embryonic development, for which somatic cell therapy would be ineffective. Although still a long way off, developments in molecular genetics suggest that this is a goal towards which biomedicine could reasonably devote its efforts."¹⁰ Once a Bishop of Delhi also said "One cannot see anything intrinsically forbidden or evil in gene therapy, whether somatic or germ-line."

Karl Rahner, a Roman Catholic theologian, while discussing the interaction of the material and spiritual dimensions of human nature, described the evolutionary history of the human race in terms of 'becoming'. Human becoming consists in the self-transcendence of living matter (David Hyed in his *Genethics* also speaks in the same tune). Nature has a history, and this history develops toward the

9. I do not have any idea of Hindu theologians standpoint.

10. Catholic Health Association of the U. S., *Human Genetics: Ethical Issues in Genetic Testing, Counselling, and Therapy*, 1990, 19.

human experience of freedom in the spirit. But Rahner and Hyed do not stop here. For them, the human race is not merely a spiritual observer of material nature. Nor is human history limited to cultural history. Human history is “also an active alteration of this material world itself.”¹¹ We human beings apply our technical and planning power of transformation even to ourselves. As subject we are becoming our own object, becoming our own creator. Curiously, what Rahner is describing here is human nature.

Karl Rahner observation makes it plain that self-transcendence and the possibility for something new belong indelibly to human nature. Human existence is ‘open and undetermined’. In saying this Rahner comes very close to Rabindranath Tagore. Tagore also emphasized on the infinite possibilities of human nature. That to which we are open, says Rahner, is the infinite horizon; we are open to a fulfilment yet to be determined by ‘the infinite and the ineffable mystery’ of God. If we try to draw any axioms that connect sublime theological vision to an ethic appropriate to genetic engineering, then openness to the future can be translated into responsibility to the future. Such a theological vision undercuts a conservative or reactionary proscription against intervening in the evolutionary process. Rahner describes the temptation to condemn genetic research and its application as “symptomatic of a cowardly ... conservation hiding behind misunderstood Christian ideals.”¹² The health and well being of future generations not yet born is a matter of ethical concern when viewed within the scope of a theology of creation that pictures the human being as the created cocreator. It is the vision of future possibilities, not the present status quo, which orients and directs ethical activity. When

11. Karl Rahner, “Christology within an Evolutionary View”, *Theological Investigations*, Vol V (22 volumes), London: Darton, Longman & Todd, (1961-1988), p. 168.

12. Rahner, *Theological Investigations*, IX: 211.

applied to the issue of germ-line intervention for the purpose of enhancing the quality of human life, the door must be kept open so that we can look through, squint, and focus our eyes to see just what possibilities loom before us. This will include a realistic review of the limits and risks of genetic technology. But realism about technological limits and risks is insufficient warrant for prematurely shutting the door to possibilities for an improved human future. Rather than playing God or usurping God's power, seeking to actualise new possibilities means we are being truly human.

We have seen that one of the sources of the fear of playing God is the science fiction. The message that these fictions carry is that though we begin with the best of intentions in exerting human creativity, the result may include negative repercussions that escape our control. The same is the risk in germ-line intervention. Due to our inability to see the whole range of interconnected factors, we may inadvertently disturb some sort of existing balance in nature and this disturbance could redound deleteriously. Socially, it could contribute to stigma and discrimination. The very criteria to determine just what counts as a 'defective' gene may lead to stigmatising all those persons who carry that gene. The very proffering of the image of ideal child may give rise a sense of inferiority to those who do not measure up. To embark on a large scale program of germ-line enhancement may create physical and social problems which will make us blame the human race for its pride, its hubris, its stepping beyond its alleged God-defined limits that brings disaster upon itself.

But the challenge that confronts us can be seen from another angle. The correlate concepts of God as the creator and the human as the created cocreator orient us toward the future, a future that should be better than the past or present. One of the problems of the

arguments given in the preceding paragraph is that they implicitly assume the present state of affairs as adequate. These arguments tacitly bless the status quo. The problem with the status quo is that it is filled with human misery, some of which are genetically caused. Is it not possible for us to envision a better future, a future in which individuals would not have to suffer the consequences of diseased genes? I fully admit that we should be cautious and prudent and recognize the threat of human hubris. Still, our ethical vision cannot acquiesce with present reality. It must press on to a still better future and employ human creativity with its accompanying genetic technology to move us to the envisioned future.

Finally, the issue of germ-line intervention is linked to what Mauron has called 'genomic metaphysics'. It implies a notion that the genome of a person is ontologically central to that person's nature, whereas all other attributes are more or less peripheral. An assumption of this sort is necessary if one is to understand why mankind is permitted to change itself by health care, immunisation, education, social conditioning, ideological brainwashing and so on, but is not allowed to touch the genome. This essentialist conception of the genome is quite problematic. Kevels is of the view that the attempt of sacralisation of the genome is an ideological move that originated with the eugenic movement.¹³ Given the fact that eugenics is a controversial issue, if somebody does not accept the argument given for eugenics, then the question arises why should we respect the genome more than any other contingent aspects of human nature. We shall have more detailed analysis of this point when we come to the discussion of the last argument.

13. Kevels, D. J., *In the Name of Eugenics: Genetics and the uses of Human Heredity*, Knopf: New York, 1985 (Chapter 4).

The issue of eugenics

It is the third argument given against germ-line gene therapy that has proved very intractable. It involves many issues such as the distinction between therapy vs. enhancement, eugenics, slippery slope and so on. These are very controversial issues and no argument can be regarded as final here. About the issue of eugenics there are equally cogent arguments for and against it, and the settlement of this issue is so difficult that it demands a separate paper to deal with this issue. However, keeping in mind the space limit our discussion will be very brief and selective.

Let us start with the conceptual distinction between therapy and enhancement. There are two stated purposes behind germ-line therapy research. One, its aim is knowledge, the simple goal that drives all pure science. Second, its aim is better human health. The avowed ethical goal is to employ the newly acquired knowledge from research to provide therapy for the many genetically caused diseases that plague the human being. John C. Fletcher and W. French Anderson put it aptly: "Human gene therapy is a symbol of hope in a vast sea of human suffering due to heredity."¹⁴ If only this second goal is pursued the issue will not raise so much dust as it does now. Virtually no one contests the principle that new genetic knowledge should be used to improve human health and relieve suffering. Yet a serious debate has arisen that distinguishes sharply between therapy for suffering persons who already exist and the health of future persons who do not yet exist. By germ-line therapy, as we have seen, we refer to intervention into germ cells that would influence heredity and hopefully improve the quality of life for future generations. It is here that

14. John C. Fletcher and W. French Anderson, "Germ-line Gene Therapy : A New Stage of Debate", *Law Medicine and Health Care*, 20: ½, 1992, p. 31.

slippery slope begins. It is thought that germ-line intervention though at its initial stages of development will aim at preventive medicine, later this technique may be used to enhance human health, intelligence, strength and so on. It is this spectre that becomes the centerstage of all controversy. This point was put in nutshell by James R. Crumley, one presiding bishop of the Lutheran Church, "There are some aspects of genetic therapy (for human diseases) that I would not want to rule out ... My concern is that someone would decide what is the most correct human being and begin to engineer the germ-line with that goal in mind."¹⁵ If we could make a watertight division between therapy and enhancement, then we could have drawn a line (may be called lakshmanrekha) and then say that upto here we could legitimately tread and beyond this not. We could then have successfully prevented to all those steps that crossed therapeutic purposes by legislation or by some other means. But a deeper discussion will reveal that the border between the two is very fuzzy and hence the therapy vs. enhancement distinction is conceptually fragile. We have plethora of instances in favour of our view. For example, the World Council of Churches in its 1982 document says: "There is no absolute distinction between eliminating 'defects' and 'improving' heredity."¹⁶ A 1989 document reiterates this position more strongly by proposing 'a ban on experiments involving genetic engineering of human germline at the present time. Again, Kitcher says that the popular idea of using genetic interventions to restore normal functioning, only normal functioning and nothing but normal functioning, is mistaken.¹⁷ The diversity of therapeutic paradigms at work in existing somatic gene therapy

15. Quoted from Paul Nelson, "Bioethics in the Lutheran Tradition", *Bioethics Yearbook*, vol. 1 : *Theological Developments in Bioethics : 1988-1990*, Boston: Kluwer, 1991, p. 119.

16. World Council of Churches, *Manipulating Life: Ethical Issues in Genetic Engineering* Geneva: World Council of Churches, 1982.

17. Kitcher, P.: *The Lives to Come: The Genetic Revolution and Human Possibilities*, Simon and Schuster, New York, 1963, p. 213.

illustrate Kitcher's point. Although somatic treatment is identified with therapy, there are instances where somatic treatment enhances such as injecting growth hormones to enhance height for playing basketball. And in germ-line intervention geneticists will initially aim at preventive medicine; the science of enhancement, if it comes at all, will only come later. All this implies that the therapy vs. enhancement border must be considerably refined before it can become a workable and ethically relevant concept. There cannot be any logical slippery slope from somatic to germ-line gene therapy, but there is slippery slope from therapy to enhancement. The spectre of enhancement is usually expressed by the term eugenics, which have derogatory connotation. This brings us to the discussion of eugenics.

While I was going through different books to settle my view about eugenics I come across so many views that I found it difficult to decide what my position was on this issue. Some of the questions that were haunting my mind: Does the new technology of genetics promise an ever better quality of human beings or threaten mankind with a new source of enslavement? Would these developments be used to breed wiser, warmer people, or to a Brave New World in this new millennium? Would the new techniques be used only to weed out faults, especially genetic illnesses, or also to foster desired features and attributes? Are we knowledgeable enough, sufficiently wise, to make such decisions? What made the matter more complicated is the use of a large variety of terms indiscriminately and interchangeably such as euphenics, eugenics, euteleogenesis, negative vs. positive interventions and so on. It was rare to find two scholars using the same terms in the same sense. To facilitate our smooth discussion it would be better not to enter into terminological confusions but make certain distinctions as clear as possible.

First it seemed to me helpful to separate genetic interventions used for therapeutic purposes from those used for breeding purposes (i.e., to order a child with certain desired attributes). Next it seemed useful to distinguish between genetic interventions introduced to serve individuals (e.g., parents who wish a normal child or a child of high IQ) and those used to promote societal, or public policy (e.g., stamp out disease, breed wiser people). Finally, let us make a distinction concerning the method of intervention used. So we may further divide the societal section into voluntary controls (e.g., like Indian government's population policy: the way it ask, but do not force, people to limit their family size) vs. coercive controls. Having made these distinctions, it seemed possible to locate the various issues that were raised about the question of eugenics. We can make the following chart to specify each issue:

	Therapeutic goals	Breeding goals
Individual service	1. e.g., abort deformed fetuses on demand	3. e.g., artificial insemination; parents' choice of donors' features.
Societal service Voluntary	2. e.g., encourage people to abort a deformed foetus	4. e.g., urge people to use sperm from donors who have high IQs.
Coercive	e.g., require a genetic test before marriage	e.g., prohibit feeble-minded persons from marrying.

Before I start to address the issues separated and depicted in the chart, a few word about eugenics will be pertinent. The term eugenics brings to mind the repugnant racial policies of Nazism, and this accounts for much of today's mistrust of genetic science. No one expects a repeat of Nazi terror and hence asks whether human genetics represents disguised, or incipient, or possibly a new kind of eugenics? But what is ironical is that those who pose the question

often may not be certain how to define eugenics. They are almost always convinced that it (i.e., eugenics) is a bad thing, one that should be prevented. To denounce eugenics, for them, is the litmus test for someone to prove that he is socially concerned, morally sensitive.

Let us begin with the question: what is eugenics? Francis Galton, who coined the word 'eugenics', defined it as 'the study of the agencies under social control that may improve or impair the racial qualities of future generations, either physically or mentally.'¹⁸ However, it is less often identified as a science than as a social movement or policy, as in Bertrand Russell's definition: 'the attempt to improve the biological character of a breed by deliberate methods adopted to that end.'¹⁹ Had the advocates of eugenics confined themselves to study, as Galton writes, the issues would not have become a source of anxiety. On the contrary, we know from historiography that people from many countries and across a wide political and social spectrum advocated policies to genetically improve the 'race'. It is this thing that causes concern. Hence many thinkers employ a narrow definition that identifies eugenics with a social aim and often with coercive means. All eugenicists did agree that individual desires should be subordinated to a larger public purpose. Going by this standard, expansion of genetic services motivated by concern for the quality of the population would be eugenic, while the same practices motivated by the desire to increase the choices available to individuals would not be. Unfortunately, this criterion requires knowledge of motives, which may not be obvious, and are sometimes mixed.

18. Galton, F.: *Inquiries into the Human Faculty*. 1883. London: Macmillan. p. 44.

19. Russell, B.: 'Eugenics' in *Marriage and Morals*. 1924. London: Liveright. pp. 255-73.

The matter does not end here. Genetics services are generally justified on the following grounds: that they increase the options available to families and/ or that they reduce the burden of genetic disease in the community, thus saving money. It is exactly on this point that Dennis Karjala's comment seems relevant. He asserts, "All cost/ benefit reasoning in the reproductive rights area is essentially eugenics."²⁰ This is a plausible claim. If a social purpose is the litmus test of eugenics, we must assess the importance of different aims, which are not often made explicit—and when they are, may disguise the truth. We often find instances where thinkers defend abortion (which is the object of pre-natal testing) in the language of choice than that of cost savings.

A definition in terms of intention is also at odds with the use of 'eugenic' to describe the effects of individual action or social policy. A practice may be characterized as eugenic when we try to change the gene frequency by lowering the number of offspring with 'defective' genes. Here we are calling it eugenic in terms of consequences, and hence motive is no longer germane. Individuals do not ordinarily intend to benefit the gene pool by their reproductive choices. But private decisions may, taken collectively, have populational effects. If by the word 'eugenic' we also describe consequences, and not just intentions, it casts a very wide net. It would make perfect sense, given this usage, to call abortion, following pre-natal screening, eugenics—whatever the motivations for individual decisions or government funding. A definition broad enough to include unintended consequences will necessarily incorporate most medical genetics or even individual mating decisions.

20. Karjala, D. J. (1992), 'A Legal Research Agenda for the Genome Initiative', *Jurimetrics*, 32 (Winter): 121-222.

I have come across some recent discussions of 'back-door' eugenics that implicitly depend on a definition of eugenics in terms of effects. A number of critics have warned of a resurgence of eugenics as the unintended result of individual choices. In their view, the real danger arises not from state policy, but from our increased ability to select the kind of children we want. Thus the new eugenics will result from a multitude of voluntary decisions, or even demands for tests and screens, rather than from social policy designed with eugenic aims in view.²¹

Most commentators, however, still restrict the term 'eugenics' to policies pursued for a social purpose. They often add an additional criterion: there must be an element of coercion. According to this criterion, the state 'interferes with' or 'controls' or 'imposes' particular reproductive options as an effort to interfere with individual's procreative choices in order to attain a societal goal.²² Eugenics is often demarcated from genetics by this criterion.

However, if we apply the label only to programmes involving some form of coercion, we exclude a large number of individuals and policies ordinarily associated with eugenics. Many eugenicists stressed the voluntary nature of their proposals (e.g., Francis Galton, H. T. Muller). Virtually all 'positive' eugenics, i.e., which seeks to increase the incidence of desirable traits rather than reducing that of undesirable ones, would be excluded by this definition.

Moreover, there is no value-neutral answer to the question of whether a policy is coercive. Coercion has different meanings in different political traditions. To classical liberals (like J. S. Mill or Isaiah

21. Duster, T.: *Backdoor to Eugenics* (1990), New York: Routledge, P. x.

22. Holtzman, N. A.: *Proceed With Caution*, 1989. Baltimore: Johns Hopkins University Press, p. 223.

Berlin) or libertarian conservatives (such as Milton Friedman) a decision is voluntary if there are no formal, legal barriers to choice. Freedom is thus defined negatively as the absence of restraint. Coercion, on the other hand, implies the deliberate interference of other human beings' with actions a person would otherwise take. One is coerced only if actively prevented from attaining a goal. To liberals in the tradition of T. H. Green or John Dewey as well as to socialists, however, coercion is not simply a matter of legal barriers: we are free to choose only when we have the practical ability to agree or refuse to do something. From their standpoint, a situation, such as economic need, may also be coercive. For conservatives, then, the potential parents of a severely disabled child are free to abort the foetus or bring it to term. From a contemporary liberal or socialist standpoint, choice may be lacking, given the medical and other costs of caring for such a child. On this view, parents could be coerced into aborting a foetus by the threatened loss of insurance coverage or lack of social services. This is not to say that pressure would evaporate with national health insurance. Even in a socialised system, if there is no confidence in the willingness of society to care for their child once they are unable to do so, parents may choose to terminate a pregnancy against their own wishes and beliefs. Whether parents are free to choose in these situations is a question that will necessarily be answered differently from different political standpoints.

Dane B. Paul suggests another, potentially more productive tack. Let us ask what scenarios people actually fear when they express anxiety about a resurgence of eugenics, and to evaluate which of them (if any) are likely, which (if any) are possible, and which (if any) are improbable.

Concerns about eugenics typically fall into one of these three distinct classes. The first is fear of direct government programmes. Those alarmed at the prospect of state intervention often cite the Nazi experience, though they usually expect the analogue to be less brutal. Thus the biologist Salvador Luria (1989) questioned whether the genome project will transform 'The nazi program to eradicate Jewish or otherwise 'inferior' genes by mass murder into kinder, gentler program to 'perfect' human individuals by 'correcting' their genomes'. The activist Jeremy Rifkin, supported by some religious and disability rights groups, has called for a moratorium on human gene therapy research until such time as the NIH establishes a 'Human Eugenics Advisory Committee' to evaluate its implications. These critics fear a slippery slope leading to state action. They believe the government might try to design workers less susceptible to environmental insults, or to design us in other ways. 'You could see genetic engineering of human beings from the foetal level on up', suggests Andrew Kimball, who directs Rifkin's Foundation on Emerging Techniques. 'If they found that your child who's in kindergarten was predisposed to shyness, they would alter that child not to be shy.... These techniques have an enormously eugenic potential.'²³

How realistic is the fear of direct government intervention. In respect to coercive gene therapy, not very. Even if it were technically feasible, large-scale gene implantation would be an extraordinarily expensive kind of eugenics. And cost saving has always been the strong motive for eugenics. Cost-benefit considerations today are less crude and, given sensitivities about abortion, sometimes less explicit. But they remain a principal incentive for state provision of genetic

23. Saletan, W. (1989) 'Genes' R US' *New Republic* (17 July), p. 18.

services. And it will be a long time, if ever, before gene therapy or any form of 'positive' eugenics can be promoted as a way to save money.

Cost-benefit analysis could, however, produce a stimulus for 'negative' eugenics. After all, the plus side of the cost-benefit ledger is represented by the number of terminations achieved for a specified condition. The more women who are screened, and affected fetuses aborted, the more efficient the genetic service. Hence cost-benefit arguments for state support of these programmes provide an incentive to expand genetic testing and maximise the rate of terminations of pregnancy for costly disorders.

Some developed countries already sponsor many pre-natal and newborn screening programmes, including some that are mandatory. Cost-benefit considerations help to explain the vast expansion in the number of women who now undergo pre-natal testing. They provide a powerful inducement to test more women, for more disorders, at an early stage. As Neil Holtzman and Andrew Rothstein note, 'Avoiding the conception of an infant at risk for a genetic disease—or avoiding the birth of a foetus prenatally diagnosed as having one—will often be less expensive than clinical management.'²⁴

It is easy to predict that as we can screen more accurately and cheaply for more common disorders, the use of genetic tests will become increasingly routinized. Will individuals be pressured to make particular reproductive decisions as a result? That would qualify as eugenics by most definitions. It would in any case be a very unhappy development. And it is a likely one, though not as the result of state intervention. As Kajala notes, 'Given the natural revulsion that most people feel for interference through mandatory testing or, even worse,

24. Holtzman, N. A. and Rothstein, N. A. (1992), 'Eugenics and Genetic Discrimination', *American Journal of Human Genetics* 50, p. 457.

mandatory abortion, the issues [of 'genetic freedom and genetic responsibility'] are likely to be raised obliquely' through the health insurance system, HMO policies, or doctor pressure.²⁵

But pressures can be indirect and involve actors other than the state. We may not soon reach the stage of compulsory eugenic legislation, denying health-care coverage because of genotype could exert pressure on at-risk families to avoid having children with disabilities, despite the families' wishes'. In fact, these are the anxieties most commonly voiced when people say they fear 'eugenics'. They worry that tests, screens and therapies will be introduced and promoted because they have the potential to generate profits for biotechnology companies, savings for employers and life and health insurers, and protection against malpractice suits for physicians—and that they will lack realistic alternatives to the decision to be tested or to abort a foetus identified as 'defective' as a result of policies adopted by these quasi-public or private actors. The problems will intensify as carrier and predictive tests for common disorders (representing large markets) become more reliable. That an insurer, rather than the state mandates a test does not necessarily make its consequences less drastic.

In the absence of public policy designed to prevent misuse, the conjoined interests of powerful non-state entities, such as physicians, lawyers, insurers, and biotechnology firms, will often drive reproductive decisions. These are entities over which the public has limited control—precisely because they are private. In some formulations, this is a subtler version of the coercion about state action. Thus Robert Wright suggests that the real threat is not a government

25. Karjala, D. J. (1992) 'A Legal Research Agenda for the Human Genome Initiative', *Jurimetrics*, 32 (winter), p. 159.

programme to breed better babies. The more likely danger, he writes, is roughly the opposite; it isn't that the government will get involved in reproductive choice, but that, it won't. It is when left to the free market that the fruits of genome research are most assuredly rotten.²⁶ In any case, this package of problems is certainly real, whether or not it is labelled eugenics.

The real problem is that once the principle of choice in respect to a non-medical condition is admitted, it is hard to know on what grounds it can be denied to parents who want to give their child a competitive advantage with respect to intelligence, height, or other socially desired characteristics.

Whether we want to start down this road is a question worth asking, whether or not we subsume this choice under the term 'eugenics'. It is also the one we will have hardest time thinking through. The reason, in brief, is this: those who are most concerned with these particular (mis) uses of genetics tend also to be the most committed to the principle of reproductive autonomy. If the latter is considered an absolute right, we will have to accept a certain amount of 'back-door' eugenics, under whatever rubric. A situation in which prospective parents can order the genetic characteristics of their offspring will also reinforce socio-economic inequality, since those at the top of the scale can purchase (and for cultural as well as economic reasons want to purchase) more genetic services than do those at the bottom. This is not a future that many critics of the new genetic technologies would welcome. But it seems to be the path down which we are heading—unfortunately by default, rather than as the result of reasoned debate.

26. Wright, R. (1990), 'Achilles Helix', *New Republic* (9 and 16 July), p. 27.

Now let us look at the chart we have prepared. As we have separated all the issues it would be easy to spell out how I think about each box of genetic tools.

Individual Therapy

Cell 1 (or individual therapy) generated by the intersection of these coordinates does not pose much problem. There is little reason for not providing individuals with all the genetic therapeutic services they would be willing to use. No religion or government should force parents to give birth to severely deformed children, and to force into the world children doomed to a distorted, miserable life. Any sort of genetic intervention (including germ-line therapy) for the above purposes should be made available to all. It is a scourge of our society that many of these genetic interventions, like many other forms of advanced medical services, mainly help the well-off, largely because the poor are less informed and more economically constrained.

Even for therapeutic goals these beneficial uses of genetic intervention should be used with certain precautions. New techniques should be made available only after they are well tested. We should be watchful of the corporations seeking to make a quick buck from new techniques. Once genetic techniques were proven sound only under one condition their application should be curbed: if there were good evidence to show that providing such services to individuals would cause serious, clear, and present harm to society. An unlimited priority of the individual over society should not be given. It is on this principle that we support even court's interference to curb pollution in metropolitan cities by limiting the movement of the pollution making vehicles(as recently we have seen in some metropolitan cities in our country).

Having discussed the various facets of individual therapeutic goals, we come to the conclusion that new genetic therapeutic techniques should be allowed as it would bring much joy to parents and children, and cause little discernible harm.

Societal Therapy

Cell 2 of our table does not admit of so easy solution. Let us imagine a situation in which society has a therapeutic goal but the individuals don't go along with them. At first glance, this may seem absurd: how can we speak about a society that has therapeutic goals other than those of the individual members. That this is quite possible can be gleaned from non-genetic areas. Let us take the instance of smoking. Antismoking campaigns are promoted by government. If individuals were really willing to heed sound medical advice, these campaigns would be unnecessary. But because of addiction society does enter the picture. Society employs voluntary methods (propaganda) and economic pressure (high taxes on cigarettes). Thus, society's forcing of its members to attend to their health is far from an unknown phenomenon. Could society step in, on the same grounds, concerning genetic matters?

At first glance it seems that coercive genetics—the use of society's laws, courts, jails, and policeman—to force the weeding out of undesirable genes is intolerable and repugnant. Unlike the abuse of one's health by means of smoking, the union between two persons, which gives life to a third one, should be kept free of all government intervention. One need only think of what would happen if some official decided that in order to reduce criminality, chromosome tests on all pregnant women would be required and abortions demanded of all mothers who carry XYY 'criminal' fetuses. We would end up with

policemen dragging women to abortion clinics and mothers going underground to protect their embryos. If the government uses its force with respect to these matters, it would constitute the ultimate violation of the contract that keeps people tolerant of the state. It would completely undermine the legitimacy and the moral basis of government. Therefore, if any attempt is made to move in the direction of coercive intervention, citizens should meet it with the utmost opposition. It is for the possibilities of coercive intervention that many call for setting up the strongest possible barriers against them.

What is opposed here is forced genetic interventions, not the setting and promotion of genetic goals. Individuals are often shortsighted selfish. They act as though they are the only ones in need and disregard the fact that what might work for one often will not work if all individuals act in the same manner. Hence there is good reason to take into account societal needs—those future, aggregate, and shared needs of the people who make up a given society. But these needs be met not through the use of force, but through voluntary means. Which of the variety of voluntary means should be relied upon depends on the circumstances.

Another reason against coercive means is that genetic illness cannot be overcome the way other diseases can be such as Polio. Testing everyone's Chromosomes and pulling out all the sick genes will not rid us of genetic illness. The basic reason is that nature continues to produce new supplies of such genes through mutations. These are like printing errors, however carefully we set the type, even if it is free of errors, for every X-thousand print-offs (or children to be conceived), a certain number will be defective. Thus even those genetic illnesses that result in the early deaths of all carriers before they have children do not disappear.

It has been argued by many that the whole attempt at genetic public policy is a waste of time, that it is hopeless. However this is clearly not the case. While we may not be able to reduce the defective rate, we can at least catch nature's errors and eliminate them before they torment our children and agonize many parents. We may well have to repeat the process for each generation, but this does not make it without value. While it would be preferable to eliminate these illnesses once and for all, the next best thing is to eliminate their consequences—their human and economic costs.

Thus about cell 2 of our chart our conclusion is that we should advance public policy of genetic interventions for therapeutic purposes, but by voluntary means, not by coercive means under any circumstances. This brings us to the next half of the exercise. Should we use genetic interventions, not to remove or otherwise overcome sickness-producing genes, but to promote those genes, which are believed to carry, desired qualities, ranging from a more attractive complexion to higher intelligence.

Societal Breeding

The use of genetic techniques for improving genetic qualities raises a quite different set of questions. This form of genetic intervention is discussed most often from a societal viewpoint, because it is here that the best-known attempts at breeding 'better' people have been made. In the past these efforts were directed toward goals that almost all people find abhorrent, especially those by the Nazis. They tried to breed a 'master' race, using such abusive techniques as the extermination of those whom they felt had inferior genetic qualities (not just Jews, but also feeble-minded Aryans and other populations). Again, the very notion of selective breeding brings to mind the secret

society in some parts of U. S. A. organised in 1915 and known as Ku Klux Klan.

But was it time to examine these taboos? Could we simply dismiss out of hand all the promised lands that are within our reach? Many scientists consider it rash simply to brand 'unthinkable' the promise of breeding a race who would have freedom from gross physical and mental defects, have sound health, high intelligence, general adaptability, integrity of character and nobility of spirit. Why dismiss the notion of using biotechnology to create people with, as H. J. Muller puts it, "a genuine warmth of fellow feeling and a cooperative disposition, a depth and breadth of intellectual capacity, moral courage and integrity, an appreciation of nature and art, and an aptness of expression and communication?"

The new era is unlikely to return us to Fascist notions of genetic determinism, but instead, will move public policy toward a synthesis, which would rely on both educational and biological factors. The synthesis era will be concerned with their combinations and interaction. The new era seems to show more interest in and tolerance for genetic engineering than ever before, but without going overboard and seeing it as a cure-all. One cannot dismiss out of hand the notion that our drive to govern our condition, rather than being subject to the blind fluctuations of forces we can neither understand nor control, might be helped through biological engineering in addition to institutional reforms and power redistribution.

The curse of modernity is that the revolutionary expansion of means—of instruments—have rebelled against the creator and his purposes. Like a Frankenstein's monster, technology has gone beyond

the control of its maker. It distorts society to fit the logic of instruments rather than to serve the genuine needs of its members.

The primary mission for the next era is the restoration of primacy of human values. This may be, reflected, in the willingness to trade off at least some economic growth and technical progress for more humane work and a greater care of nature. The problem is that, at present, all efforts to restore the primacy of human values over tools—by expanding our brainpower and wisdom—have not progressed very far. Efforts to do so via institutional reforms, social revolutions, or rejuvenation of self seem to provide at best only partial solutions. Hence one has to consider the notion, advanced by H. J. Muller and others that a 'higher', less aggressive, more intelligent breed may have to be biologically cultivated before a more humane society can arise. As one biologist, James F. Danielli, puts it: "From the point of view of genetics, man is a barbarian clad in the trappings of a civilization in which he is ill at ease, and barely able to contend. Social scientists pin their hopes for easing this unfortunate state on possibility of improving human institutes and environments. But with human genetics as it is this is a most dubious proposition."²⁷ The author goes on to define the sources of our problems as nationalism, aggressiveness, and excessive bureaucratic inclination, all of which render society unmanageable. He suggests that genetic engineering could help remedy all these proclivities.

But it is downright naive to believe that in large organisations the tendency to malfunction has a genetic base. If people tend to be lethargic, can education turn them into a productive and creative race?

27. James F. Danielli, "Industry, Society, and Genetic Engineering", *The Hasting Centre Report* 2, 6 (Dec 1972) p. 7.

It seems to me that we must draw on both social and biological factors if the human condition is to be bettered.

Anyway, I do not think a breeding policy will be abominable to society. Would not most of us like to grow more intelligent and warmer persons? It is exactly the aim of our educational policy. And who said we need a uniform race? Could we not breed some of each kind? Since the implementation is to be voluntary, there will be no more uniformity than people will choose to have. At issue is a public policy, which welcomes certain biological qualities. This is rather similar in nature to our call for limiting the family size. Some are influenced by it, others ignore it. Similarly, in the case of breeding policies, even if there were one recommended fruit, many would not buy it. And if some attributes do prevail, it would be because many people accept the policy. In short, I do not see a contradiction between such a genetic policy and a democratic society.

Several biologists have argued that breeding a superior race is all pie in the sky. For them, such breeding is technically infeasible in the near or even remote future. The whole argument is unnecessary, they say, because no such changes can be effected. As mandatory and uniform policies are out of the question, voluntary adherence would be limited in scope and hence in effect.

Having learned the arguments of supporters of genetic intervention and its critiques, I have come to feel that the truth probably lay, as it so often does, somewhere between the extremes, between the advocates and the deriders. To my mind, unless someone could bring up a new argument against a public policy that would encourage people voluntarily to favour certain traits, it should not be opposed. A limited genetic experiment might be acceptable. It has been argued

that even such a limited experiment would require twenty generations to complete because of the slow accumulative effect of such changes. The scope of the effect depends, of course, on how many people will choose to heed the genetic suggestions and the extent to which they will marry each other rather than 'outsiders'. As the benefits will almost surely be gradual and not sensational, there is hardly any reason to oppose them.

Thus while arguing we must separate 'voluntary eugenics' from 'coercive eugenics'. Voluntary eugenics, publicly promoted, freely accepted or refused need not be opposed. Coercive eugenics, those imposed by the state, which must be abhorrent to all, must be fought by all means known to human beings, like other totalitarian policies.

Now, what is one to say about individual seeking to breed children the way gardeners seek an attractive hybrid of flowers? One may be reluctant to favour a public policy on the side of genetic improvements—but how about individuals shaping the genes of their offspring to their own heart's desire?

Individual Breeding

The above question brings us to the issue of gene shopping. Gene shopping, choosing and combining the biological qualities of a child yet to be conceived and designing it to the parent's preferences, is discussed chiefly in science fiction and occasionally in press. As gene shopping is a remote idea many feel that it is quite unnecessary to worry about the wisdom, ethicality, or social consequences of developing genetic supermarkets. Experts maintain that gene shopping is a long way off because most of those biological attributes, which are genetically determined, are controlled not by one, but by several genes, acting together in ways far from fully understood. Moreover,

most of our attributes are shaped in an interaction between our genetic inheritance and our psychic and social upbringing. Last, but not the least, we know from breeding domesticated animals that if we push one attribute, we tend to weaken most others, ending up with a highly vulnerable, unbalanced species. Gene shopping, then, seems to hold much less promise than its outspoken advocates have claimed.

But it does not follow that one need not discuss the implications of breeding to individual order, because some gene shopping is technically possible right now. The issue they raise, at least psychologically, are not different in principle from those that will be raised by the future developments. Because of early technical and related social developments, the question must be faced, and the sooner, the better. Sex choice is a case at hand. When a test is done to determine if the foetus has some genetic illness, its sex is often determined as well. The development of sex choice techniques makes it possible to choose sex. The question, then, cannot be avoided: Should parents be allowed to choose their child's sex, and, by implication, other genetic qualities, a choice which obviously is not one of health over illness, not a therapeutic matter at all, but clearly one of the breeding?

As long as sex choice entails abortion this procedure is tolerable for therapeutic, but not for breeding, purposes. But who should have the right to decide? We, in India, already allow parents to abort children in order to limit their family size, hardly a therapeutic goal. We say that both parents and children would be happier if there are no more than two children per family. Now, should doctors or the state decide that parents are not allowed to plan their children—their sex and soon other attributes—only their number? And what if a family of four boys feels one girl essential to make it happy? It seems to me

the decision should be up to the parents. It is understandable that the aggregate consequences for society, if its members freely choose the sex of their children, would be quite undesirable. But these consequences are not severe enough to warrant limiting the development of sex-choice techniques. I recognize that society has needs of its own and that a severe sex imbalance could damage these. However, by my calculations the damage would not be considerable, for the present son-complex will surely decline with the impact of women's liberation.

Thus I hold that since society is not likely to be seriously undermined by such techniques, we should not prevent individuals from gaining whatever happiness they can. If this entails adding a boy or a girl to their family, why not let them? It seems to me the same holds true for other means of genetic shopping now available. If we allow people to gamble on winning a fortune in a state lottery, it seems to me that we could not prohibit them from trying to improve the biological lot of their children.

Now let us see what we could tolerate and what we should oppose: Genetic interventions for individual therapy needed more support. Social force should not be applied for either health or breeding purposes. Voluntary promotion of public policy in genetic matters makes good sense. Individuals should be free to breed what they wanted to. Steps, however, must be taken to see that the public is better informed as to what to expect, so that they can make wiser decisions.

One thing always leads to another. If we open door to genetic engineering of one kind, will it not lead to the other, less desirable forms? Would not voluntary firms turn into coercive ones as

governments become attracted to prospective gains? Neat conceptual chart, I am aware, do not keep social forces within their boundaries. Actually, one of the arguments most often made against genetic engineering, as we have seen, is that to engage in it is to step on a slippery slope: once we lose our footing, we find ourselves on our backside at the bottom of the slope. Some fear that once we use genetic interventions for therapeutic purposes, they will also be used to breed people. Others think that once they are allowed for individuals, governments will also use them. Still others feel that what might start out as a voluntary public policy in a free society may end up as a coercive measure used by a devilish totalitarian government to xerox a million copies of super soldiers or secret agents. Finally, a slippage of moral is feared. Once we start making babies on assembly lines, what will happen to the family—indeed, to the sanctity of human life?

Little hope for avoiding the problem could be expected from the techniques themselves, because the interventions, which work for one goal, could also be used for others. Like master keys, they open a large variety of genetic doors. Thus genetic techniques could serve as both healers and breeders, to advance individual needs as well as societal goals.

But what a society should do? Not step on the 'slope' at all? No one should oppose all genetic interventions because this stand wreaks misery on people, misery we know how to avert. It seems inconceivable that such genetic information and medical help will be withheld in the name of such an abstract notion as a slippery slope. Thus, morally, we have no choice but to set our foot on the slope and negotiate it part of the way. We shall have to find ways to stop from rolling down, but we cannot afford to allow fear of the lower reaches to keep us from reaping the benefits awaiting us at higher reaches.

The other slippage about which various commentators worry lies in the means used to promote public policy in this field. A government, it is said, could start with completely voluntary efforts (the way we now try to persuade people to have smaller families), go on to exert economic pressure, and from there take outright coercive steps. There is no denying that there is such a danger. But one must note that such slippage is not as inevitable as those who point to it often imply. There is public debate, a political struggle, and even moral assessment, whenever means of control are changed.

Finally, some observers worry about moral slippage. There are now several mores agitating against the notion of genetic engineering, including those, which extol the family, the taboo against recognized racial differences, and the values that stress the sanctity of human beings. Once tampering with all these becomes acceptable, there would be a further weakening of the moral veneer that keeps people civilized and keeps others viewing fellow being as ends rather than means. These might be affected by genetic engineering, although there are scores of more powerful factors that challenge them.

However, the historical record shows that while some taboos surely did gradually weaken, others were reset. In short, slippage is not a foregone conclusion. Our choice is not limited to a technological free-for-all or a conservative clinging to traditional norms. We have more options than to remain fearfully stuck at the top of the slope, afraid to pick up fruits growing midway, out of fear of ending up at the bottom on our collective rear end. If wiser public policies are to be formed, we must further evolve our capacity to reset taboos instead of being frozen in by them or breaking down into anarchy.

The next argument of our list is concerned with transgenerational gene therapy where it is argued that it is a non-consented therapy on not-yet-existing people. It is said that we will be held accountable by future generations for the wrongful damage we inflict on them.

This argument can be met in two ways. On the one hand, the present generation will not be around in the future and hence they cannot be held accountable in the sense that they can be punished by imprisonment. Of course this is not an ethically sound argument. Just because we cannot be punished does not mean we are not accountable in a moral sense. But the other side of the argument is equally convincing. Though absent, we can be held accountable by our progeny in the sense that future finger can be pointed to us for our failure to assume responsibility.

Suppose we draw up the previous concern for accountability and combine it with the concepts of rights and wrongful birth. Then the questions are: Might future generations blame us for their wrongful birth by damaging them through germ-line intervention? Or, in contrast, might they blame us for not intervening in the germ-line, thereby leaving them to suffer from diseases we could have prevented? We are at an ethical crisis—that is, on the verge of an ethical challenge where creative action is demanded—because whether we engage in germ-line intervention or not, if we are technically capable, then we will be held morally accountable. Here a contrast with the environmental crisis is illuminating. We can imagine our posterity on a deforested earth, mines depleted of their minerals, lakes dead from acid rain, food supply contaminated by chemicals, skin cancerous due to depleted ozone layer, raising their finger at us in anger. They will claim we violated their right to a life-giving environment and hence are accountable.

The penultimate argument given against germ-line modification is that it will reinforce existing social discrimination. Discriminations for various reasons. One such reason may be only economically well off will be able to afford it whereas others will lag behind and hence they will be treated as 'damaged goods'.

In order to counter the above argument it may be said that it is an obvious fact that discrimination in various forms already exist in society at present. Discrimination seems to flourish quite well without germ-line manipulation, yet somehow this is alleged to count as an argument against the latter. If the argument rests on the premise that germ-line enhancement will create a technical ideal achievable by some but not others, then it falls on the grounds of triviality. This could apply to countless ideals in our society. We daily confront innumerable ideals that are met by some but not all. Given the realistic prospects for what germ-line enhancement is aimed at accomplishing, the new situation would not alter the present situation in this respect. If it is technically possible to relieve some individuals from suffering, then this achievement for those afflicted will only lead to feel gratitude on their part and of those who love them.

One could envision a next step, of course, where germ-line intervention could, if made universally available, eliminate the likes of diabetes from the human gene pool. We would then have a future wiped clean of genetically based diabetes. If this constituted an achieved ideal for the whole human race then why we should not attempt to approximate that end. If it is technically feasible then gradually it will be made economically viable and hence the question of prejudice and discrimination will have no relevance.

What if we were to falter somewhere along the way? Suppose we began a worldwide programme to wipe out the predisposition to diabetes (a predominantly genetic disease) from the human gene pool achieved success in some family or ethnic or class groups, and then due to lack of funding or other factors had to abandon the project. What would happen to those individuals who still carried the deleterious gene? Would they suffer stigma or discrimination? Perhaps, yes. Yet, we might ask, does this prospect provide sufficient warrant to shut down the research and prohibit embarking on such a plan? Rather we need meticulous planning and a strong determination to accomplish it successfully.

As to the assumption that germ-line intervention implies biological perfectibility and, on account of this, that human persons will be regarded as artefacts, it may be said that it does not seem to apply to the actual situation in which genetic scientists currently aim. It is important to bear in mind that genetic scientists are occupied with much more modest aspirations such as protection from monogenetic diseases. The medical technology here is not much beyond infancy. What is genetically desirable is by no means scientifically attainable. What about the social psychology of feeling like 'damaged goods' or being treated like 'damaged goods'. If a technically achievable ideal should become a cultural norm, then those who fail to meet the norm would understandably feel inferior. Would it cause a possible loss of human dignity? At this point a reaffirmation of human dignity is called for wherein each individual person is treated as having the full complement of rights regardless of his or her genes. Ethical support here comes from the religious doctrine of creation, wherein God makes men and women in the divine image and pronounces them 'good'. God loves each human being, regardless of health or social location or

genetic endowment and this recognition should translate into social equality and mutual appreciation.

This is now time to turn our attention to the argument that future generations have the right to inherit a genetic endowment that has not been intentionally modified. This argument has been dealt with partially while we were discussing earlier arguments. To my mind, this argument can be effectively answered if we can determine whether genes have moral status. The question, to be precise, is whether we have moral obligations towards genes, independent of any obligations we may have towards the organisms of which they are, were, or will be part.

To have moral status is to be an entity towards which moral agents can have moral obligations. We usually assume that human beings have moral status, but that their blood, bones, and other body parts, systems, or tissues do not. Of course, it is generally wrong deliberately to injure a persons' body; but the wrong is assumed to be a wrong against the person, and not against the injured part. We also assume that any nontrivial body part, such as tonsil, may---with the person's consent---be removed, if it has become incurably diseased, and a serious liability to the persons health. And when a persons survival is at stake, even so vital organ as a heart may---with the prior consent of donor and recipient---be removed and replaced with another one, with no independent moral concern for the organ that is removed. These common assumptions are consistent with the major philosophical theories of moral status. Each of these theories promulgates a single criterion of moral status, based upon some property possessed by some or all living organisms. Immanuel Kant, for example, argues that only moral agents are ends in themselves; and that all other organisms are mere things, towards which we can

have no moral obligations. Albert Schweitzer, on the other hands, defends a principle of equal moral status of all living organisms, from human beings to the simplest microorganisms. Again, Peter Singer defends sentience-based criterion.

We have seen the common assumptions. But there is no dearth of the opposite view. Some extraordinary religious and symbolic meanings have already become associated with the human genome. As Dorothy Nelkin and M. Susan Lindee point out, human DNA has been used as a symbol of individual human identity, and of the human spirit, soul, or essence. Many are inclined to view the human genome as a sacred territory, a taboo area, that on account of its spiritual importance it should never be manipulated. The tendency to attribute a special moral or spiritual significance to DNA can be found in both religious and scientific writings. John Noonan, for example, maintains that conception is "the decisive moment of humanization," because, "at conception the new being receives the genetic code. It is this genetic information that determines his characteristics, which is the biological carrier of the possibility of human wisdom.... A being with the human genetic code is a man."²⁸ Scientist, too, have been willing to view the gene not only as a powerful biological entity but also as a sacred text that can explain the natural and moral order. For instance, Richard Dawkins speaks of genes as, in effect, the true locus of human agency. He is aware that genes have no foresight. They do not plan ahead. Yet he describes their activities as though they were conscious agents, with a sense of self, and their own self-centred interest.

Booth Noonan and Dawkins impute to genes properties that might once have been attributed to the soul. For Noonan, genes

28. Hubbard, R. and Elijah, w.: *Exploding the Gene Myth. How Genetic Information is Produced and Manipulated by Scientist, Physicians, Insurance Companies, Educators, and Law Enforcer*. Boston: Beacon Press, 1993, p. 9.

constitute the human essence, that which makes us uniquely valuable beings. For Dawkins, genes are powerful---even godly--- beings, which calls us into existence, and which enjoy a form of immortality that human and other organisms do not.

Thus we find two diametrically opposite views: one view treats gene like other parts of our body and the other view treats gene as sacred. Perhaps there are reasons for treating DNA differently from other body parts. There are strong arguments for regarding human germline DNA as an inappropriate target for alteration, at least at the present time. There are legal, social, and ecological arguments against the patenting and monopolistic commercial exploitation of either human or nonhuman genes. If people throughout the world agreed to grant a special moral status to genes, perhaps some of the gravest risks posed by the new genetic technologies could be avoided. But this argument hold good for two reasons: one, for our insufficient knowledge about gene; second, the socio-economic discrimination that gene tinkering may bring about. These two points have been touched and answered while dealing with earlier arguments.

However, talk of claims of the future generations of genetic patrimony is a bit awkward for it seems to imply that these generations already exist in some sense and are presently making claims upon us. Rather it seems happier to think in terms of our obligations to future generations. There are many specific sorts of obligations we might think of in connection with future generations. For example, we have obligations not to spoil the environment for them or use up valuable natural resources or leave behind sources of danger like spent nuclear fuel, unexploded nuclear weapons, or other dangerous pollutants. However, it is convenient to think of all these specific obligations we might have towards future people as obligations not to harm them.

There are two possible ways of bringing about harm. One is by using positive actions and deliberately changing things so that harm results. The other equally effective way is by deliberately leaving things as they are, knowing that harm will result--using so-called 'negative actions'. It would obviously be as bad, say, to pollute the environment so that the incidence of cancer is increased by 20 per cent as it would be not to remove a naturally occurring environment hazard when we could easily do so and failure to remove it would cause the same degree of harm. Our obligation not to cause harm to future generations has the same positive and negative faces. 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 that, 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 that will adversely affect their descendents. On the other hand we must not fail to remove genetic damage that we could remove and which, if left in place, will cause harm to future people

We must in short weigh upon the probability of harm occurring as a result of what we do, against the probability of harm occurring if we fail to take steps now to prevent its future occurrence. In some cases the dilemma may be acute, we may simply not know enough to be able to make reasonable judgements as to the various probabilities involved. In such cases we should err on the safe side. It is right that the safe side is always supposed to be the side of preserving the status quo. But if it is, should we avoid, modifying the germ-line if we have good reasons to suppose that there may be adverse effects. However, we should not fail to remove a danger that is real, present, and certain for fear that there may be some adverse

consequence which we have no reason to expect but which might conceivably occur. Sure, we should be cautious, but we should not be negligent. And it would surely be negligent to deny human beings the benefits and protections that gene therapy will surely make possible.

Conclusion

I do not consider the heightened sensitivity that we find in different fora about the consequences of modern biology as intrinsically bad. Neither is an intense public debate over such matters. However there is a serious problem when philosophers and social scientists dominate the public debate about biotechnology. Most of the times they are more concerned with ideological agendas and the horrors of history than with biotechnological realities. Learning from history is indispensable. However history can also become an excuse for avoiding critical and important questions. I certainly want to make sure that everything which goes on in the program is conducted in an ethically acceptable way. But I differ with the argument that you must foresee and resolve every legal and ethical eventuality before the research is allowed to start

Genetics today is not the same as eugenics and racial hygiene in 1930s, which were more concerned with technocratic solutions on the level of whole populations than with any detailed understanding of the role of genes in development and disease. This is not to say that modern genetics does not pose serious challenges and that a society should not have the right to establish limits as to what it finds acceptable. But such a decision should only be made after an informed discussion based on a proper understanding of the scientific issues and the relevant historical background. Framing the debate exclusively in the context of literary images (Mary Shelly's

Frankenstein, Aldous Huxley's *A Brave New World*, Goethe's *Faust*, or Nietzsche's *Thus Spoke Zarathustra*) or the crimes and ideology of the Nazi period is not enough. The common theme in the literary models evoked in this debate is that man will give in to temptation and will try whatever is possible inevitably leading to disaster. History, and in particular the Nazi period, then only serves to confirm these fears and leads to fatalistic attitudes toward biotechnology.

Railing against the dangers of biotechnology from a position of presumed moral authority will not ensure that the practice and governance of modern biotechnology becomes any more democratic. The benefits of biotechnology, in particular its medical applications, are clearly visible to everybody. But there are also indisputable problems, especially when economic interests are at stake. As the recent controversies over agricultural practices (mad cow disease and dioxin) and genetically manipulated food demonstrate, ignoring concerns about safety or traditional values inevitably leads to a backlash. This is even more the case in areas that involve questions of morality and human self-understanding, such as germ cell therapy. Here it is especially important to abstain from moralistic or economic grandstanding and to consider both the factual realities and the concerns of citizens when making decisions.

Informed (public) discussion requires informed (public) participants. But whose responsibility is it to educate the general public about the admittedly complicated issues of modern biology and biotechnology? Clearly this situation poses a challenge to scientist. In a developing country like India National academies and various scientific societies should initiate programmes to encourage scientific literacy. Equally important are efforts to popularise science in order to reach a wider audience. Scientists need to speak out on matters of importance

for society and politics. They should be willing to popularise their results and to express their views in popular media. Unfortunately there is a tendency of scientists to remain enshrined in the ivory tower of pure science. Philosophers, of course, can play a role there. Some philosophers, such as Earnest Cassirer, were in constant dialogue with leading scientists, and tried to integrate the results of science into their work.

Although still in its infancy, biotechnology has breathtaking possibilities for improving human health and nutrition. The development of this technology is not recreational. Through this technology scientists are attempting to solve the real-world problems of sickness, hunger, and resource depletion. There is a considerable likelihood, and I am aware about this, that future for-profit research in genetics will increase inequalities between rich and poor nations and between rich and poor people within each nation. It is this issue that needs to be adequately addressed to. Social scientists should devote time to minimize this disparity. The results of gene therapy, whether it is somatic or germ-line, may benefit only to those who can afford them. Our posterity may inherit a social world more deeply divided by socio-economic class and ethnicity. We could envision a time when those who can afford it, routinely use genetic therapy to improve upon their germ-line DNA. In this scenario, the class distinction between the wealthy 'Genrich' and the impoverished 'Naturals' becomes so deeply institutionalised that there is no movement from one class to the other. In this dark scenario the only silver lining is that there is now increasing international recognitions that benefits should be more equally distributed.

However, the issue surrounding benefit sharing is complex. Should it be specific to families or communities that contributed to research? Should it be limited to those with particular disorders, or

should it be more general? The most practical solution is that benefits be distributed broadly, perhaps to the health care infrastructures of entire nations. Uptill now we see applied research in both the industrial and academic sectors has focused on diseases commonly found in North America, Europe, Japan, Israel, Australia, and New Zealand, where significant number of people can afford the new genetic technologies. This trend will accentuate already existing difference between rich and poor nations.

Let me make it amply clear that I do not intend to take the side of any extreme. I do not favour stopping progress, curbing science, destroying technology, and returning to the Stone Age; also I do not favour a complete free reign for science, preferably with no questions asked. I favour control, but featherweight. Even if we want we could not stop science or do away with modern technology. Our concern should be what mechanisms, used in what ways, make it possible to curb some undesirable effects without hindering the mainstream of development. It is not the gene therapy in the present form that is undesirable. As we have seen, the present target of the scientists is to cure that involves only monogene. The overwhelming majority of inherited human traits, that is feared to be tempered with --- like, intelligence, height, and so on --- tend to be polygenic. For now, at least, such multi-gene targets remain beyond the reach of those who might consider employing new gene therapy techniques as a tool to shape their particular dreams of human genetic hygiene.
