

ANNALS OF THE NEW YORK ACADEMY OF SCIENCES

Volume 265

ETHICAL AND SCIENTIFIC ISSUES POSED
BY HUMAN USES OF MOLECULAR GENETICS

Edited by Marc Lappé and Robert S. Morison



The New York Academy of Sciences
New York, New York
1976

ANNALS OF THE NEW YORK ACADEMY OF SCIENCES

VOLUME 265

January 23, 1976

**ETHICAL AND SCIENTIFIC ISSUES POSED
BY HUMAN USES OF MOLECULAR GENETICS***

Editors and Conference Chairmen

Marc Lappé and Robert S. Morison

CONTENTS

Ethical Responsibility in Science in the Face of Uncertain Consequences. <i>By Daniel Callahan</i>	1
The Prospects for Gene Therapy in Humans. <i>By John F. Morrow</i>	13
Ethical Issues in Priority-Setting for the Utilization of Genetic Technologies. <i>By Sumner B. Twiss, Jr.</i>	22
Social and Political Uses of Genetics in the United States: Past and Present. <i>By Jon Beckwith</i>	46
Reflections on Issues Posed by Recombinant DNA Molecule Technology. I. <i>By Richard Roblin</i>	59
Reflections on Issues Posed by Recombinant DNA Molecule Technology. II. <i>By Stanfield Rogers</i>	66
Reflections on Issues Posed by Recombinant DNA Molecule Technology. III. <i>By Alexander Morgan Capron</i>	71
Scientific Optimism and Societal Concerns: a Note on the Psychology of Scientists. <i>By Gerald Holton</i>	82
Reflections on the Cost of Doing Science. <i>By Marc Lappé</i>	102
A Psychiatrist Looks at Scientists Looking at Science. <i>By Robert Michels</i>	112
Philosophical Considerations in the Growing Potential for Human Genetic Control. <i>By Richard T. Hull</i>	118
Panel Discussion	127
"Genetic Medicine" in Pediatric Practice Now. <i>By William J. Mellman</i>	134
The Future for Gene Therapy — a Reevaluation. <i>By Theodore Friedmann</i>	141
Gene Therapy and the Ethics of Genetic Therapeutics. <i>By Robert Neville</i>	153
Panel Discussion	162
Law and Genetic Control: Public-Policy Questions. <i>By Harold P. Green</i>	170
Reflections and Speculations on the Regulation of Molecular Genetic Research. <i>By J. Leslie Glick</i>	178
Novel Pressures on the Advance of Science. <i>By Bernard D. Davis</i>	193
Closing Remarks. <i>By Robert Morison</i>	206

* This series of papers is the result of a Conference on Ethical and Scientific Issues Posed by Human Uses of Molecular Genetics, sponsored by The New York Academy of Sciences and The Institute of Society, Ethics and the Life Sciences, and held on May 15–16, 1975 in New York City.

PHILOSOPHICAL CONSIDERATIONS IN THE GROWING POTENTIAL FOR HUMAN GENETIC CONTROL

Richard T. Hull

*Department of Philosophy
State University of New York at Buffalo
Buffalo, New York 14226*

In a time when the humanities, and particularly philosophy, are at a low ebb in the halls of that societal microcosm, academe, it is gratifying to a philosopher to be asked to address a major scientific organization on so profound a topic as the growing potential for human genetic control. I have sought in the following remarks to bring a scientific layperson's views on the topic into focus, in the belief that these issues transcend the normal requirements of training and expertise of their commentators by virtue of involving the very essence of what it is to be human — an enterprise in which each of us is engaged full-time.

I shall be employing a convenient distinction throughout my remarks, and it would be well for me to spell it out at the outset. The distinction is between microethics and macroethics.* The former is the customary sort of ethics with which we are all familiar: the principles and maxims that govern the behavior of individuals one to another. "Macroethics" I intend to cover the principles and maxims that govern the behavior of individuals as it affects whole groups. The difference is mostly one of degree, but perhaps the issue can be brought to focus with a simple illustration or two.

American physicians are not distributed evenly throughout the population; they tend to be concentrated in urban centers, and there to be located so as to be highly accessible to middle and upper-class populations, but not so easily accessible to lower-income populations. Hence, a physician may be highly ethical in dealings with individual patients — that is, ethical at the microethical level — yet open to criticism at the macroethical level in choosing to locate so as to reinforce unequal health care distribution. A second example: a medical researcher engaged in field testing of new drugs is faced with an enormously difficult task if he or she tries to obtain subjects on a culturally and economically random basis. The usual solution is to turn to lower-income classes in this and other societies and to persons who are institutionalized, and a frequent justification of this is that such persons may thereby receive improved medical care. Hence, such a research physician may well behave most ethically towards his or her individual subjects in providing health care that goes beyond that minimally required for safe administration of the drug. Yet, such a subject-selection procedure reinforces patterns of inequitable health care distribution by actually creating a justification for their preservation — the need for willing experimental subject pools whose members are rewarded for their participation with services that ought to be theirs anyway. Thus, macroethical and microethical considerations come into conflict under the pressures and needs of the immediate situation. This suggests that macroethical behavior

* The distinction was first suggested to me by Professor Barbara Ehrenreich.

involves attention to the general situations in which we participate, while microethics is concerned with our behavior within such situations.

So far as we know, *Homo sapiens* is the first species to introduce controls and modifications in its environment and intraspecific relations that permit a large-scale departure from the customary patterns of natural selection and reproduction. This is one fundamental root of individualism, in which concern for the rights and welfare of the individual takes precedence over the genetic welfare of the species as a whole. Another way of putting the point is to observe that human evolution has, with the advent of civilization, reversed the normal phenotypic responsiveness of the species to the environment; where a species normally responds to the demands of the environment by means of the mechanisms of selection and adaptation, this species remains relatively nonselective and nonadaptive, preferring instead to adapt the environment to its needs. The development of civilization and its institutions has permitted this species the luxury of elevating the individual to a position of social equality with other individuals, despite differences of genetic heritage. Monogamy, planned families and population control, lowered infant mortality and increased lifespan are all manifestations of this concern for individual welfare. This macroethical imperative, "*Act so as to maximize lifespan and reproducibility of all individuals*"† has, in its technological implementation, given rise to a whole area of microethics that regulates the activities by which individual members of the species may seek to prolong their lives and to extend their identities into future generations. The study of this area of microethics has provided a sizeable budget of problems and conflicting moral maxims, and ethicists have for years directed their efforts towards developing coherent systems of principles to deal with these problems and conflicts.

These advances in individualistic humaneness, however, are not without their price in the currency of species survival. As Hermann Joseph Muller, Nobel Prize winning biologist, put it

... the amelioration of our present biological burdens by modern medicine, sanitation, and all the other artificial aids to living is only temporary; since these devices save for reproduction many of the more defective individuals who would otherwise have died off ... they will continue to operate in this manner until, many generations later, the average individual, even with the best medical care and man-made supports, will have accumulated so heavy a load that he is just as likely to meet genetic extinction as was the man of the stone age. Moreover, he will be as much dragged down by his natural disabilities as that man was. The only way to avoid this anticlimax would be for the people bearing heavier genetic loads to refrain from reproducing, even though medical and other aids had made them able to live and reproduce. We are at present a long way off from such social motivation in reproduction.¹

Muller's pessimistic observations have prompted one ethicist, Paul Ramsey,² to speak of "the Genetic Apocalypse and the End of Man," and to consider whether the microethical issues should give way to the pressures for species survival. Ramsey argues that acquiring the means necessary to reverse the building genetic load is morally impermissible, since it of necessity involves increasing the risks to life and health of particular individuals not yet born. Molecular genetic interventions, in early experimental stages and whether in

† I permit myself here a degree of oversimplification; I should want to modify the principle in other contexts so as to reflect, for example, considerations of the quality of life.

gametes of volunteers or *in utero*, will unavoidably involve future individuals for whom the phenotypic results of those interventions will be more deleterious than would have been the results of letting them develop naturally. Ramsey thus calls our attention to the conflict of our microethical obligations with the macroethical goals of molecular genetics. Since the unborn cannot give informed consent to such interventions and thereby freely shoulder the self-sacrificial burdens required, the fundamental canons of the patient/physician relationship are frustrated. That is, on his view, flatly impermissible; however high and noble the ends to which such knowledge is sought, those ends do not justify as means any steps that contravene the moral strictures of microethics. About these and other technical developments, Ramsey concludes that "the decisive moral verdict must be that we cannot rightfully *get to know* how to do this without conducting unethical experiments upon the unborn who must be the "mishaps" (the dead and the retarded ones) through whom we learn how." (Reference 2, p. 113; italics his.)

Ramsey's solution to these problems is to sacrifice the macroethical individualistic maxim in question to the extent required to prevent the occurrence of monogenetic disorders:

The treatments for the prevention of cystic fibrosis, Huntington's chorea, achondroplasia, some forms of muscular dystrophy, PKU, amaurotic idiocy, and other chromosomal abnormalities (if and when our Early Genetic Warning System can be perfected to detect them before conception) are continence, not getting married to a particular person, not having any children, using three contraceptives at once, or sterilization. (Reference 2, p. 120).

But his view is that a permanent ban on the research necessary to develop methods for correcting genetic defects is the only moral alternative, not because such knowledge could not be used morally in therapy, but because such knowledge cannot be gained morally in experimentation. It would, on his view, be better to deny the normal individualistic liberties of sexuality and procreation for any number of individuals than to produce one mishap; better, even, to allow the genetic load to build and any number of future individuals suffer the ravages of genetic disease than to act to acquire the knowledge to avoid that suffering, if the acquisition of that knowledge carries with it the *infliction* of harm on far fewer a number as a consequence of our quest for that knowledge.

If we consider the requisite research in the light of our macroethical maxim, "Act so as to maximize reproducibility and lifespan of all individuals," it seems at first that even this maxim implies Ramsey's ban. For, if the acquisition of the means to conquer genetic disease requires the accidental production of "mishaps," then those are individuals for whom we do not act so as to maximize reproducibility and lifespan. Even if we reject the primacy of microethics over macroethics, even if we insist that it is the latter that provides the contexts and situations that dictate the parameters of the former, is there any way to counter the claim that it is impermissible to pursue the development of this knowledge, given the unavoidability of "genetic mishaps"?

I am not so inclined as either Muller or Ramsey to view the future of the species so bleakly, and my optimism turns on the advances being made in molecular genetics and in our understanding of the internal and external environments in which deleterious genes find their expression. Moreover, I am not so inclined as Ramsey to respond to the possibility of experimental "mishaps" with moral condemnation, for the alternative of allowing an even greater quantity of suffering to occur seems to me to be morally worse. Ramsey's position appears to rest either on a spurious distinction between active

and passive involvement in increasing risks for the unborn, or on a mistaken notion of relative responsibility for consequences of acting versus consequences of deliberately not acting. I do, however, see other potential conflicts between microethical and macroethical issues, and I should like to lay some of these out in conclusion.

The effect of the advances we have made and are making in molecular genetics and in eugenics is to drive a wedge between an individual's genetic heritage and his or her phenotype and genetic legacy. This is the advent of the second stage of this species' assumption of responsibility for and control of its own evolution. In the first stage, we have been overcoming the short-term individual consequences of natural patterns of selection – that state of nature in which, as Hobbes put it, life is "nasty, brutish, and short." We now see at hand the possibility of controlling the very processes by which the genetic apocalypse would otherwise eventually follow upon our individualistic humanism. Bearing in mind the distinction between monogenic and polygenic characters and the enormous and perhaps insurmountable difficulties of ever gaining control over the latter, ‡ we now contemplate acquiring the knowledge to reverse deleterious genetic mutation and its effects, while preserving individual reproductive freedom. This prospect is wholly consonant with the aforementioned macroethical imperative, and were the means to it not in apparent conflict with our microethical commitments (and perhaps our macroethical ones as well), this conference would perhaps not be necessary.

The morality-of-the-means question arises because of the apparent difference between consequences that result from undertaking some course of action and consequences that are the results of refraining from taking some course of action. There are two possible lines of response to this; one attacks the distinction between actions and nonactions, while the other admits the distinction but attacks its moral relevance. I shall treat these separately.

On the one hand, the distinction between deliberately acting with some end in mind, and deliberately refraining from some action with the same end in mind, seems to some not to be a distinction between action and nonaction, but between different actions. For example, James Rachels has recently argued the point in the context of a discussion of euthanasia:

... it is not exactly correct to say that in passive euthanasia the doctor does nothing, for he does do one thing that is very important: he lets the patient die. 'Letting someone die' is certainly different, in some respects, from other types of action – mainly in that it is a kind of action that one may perform by way of not performing certain other actions. For example, one may let a patient die by way of not giving medication, just as one may insult someone by way of not shaking his hand. But for any purpose of moral assessment, it is a type of action nonetheless. ... If a doctor deliberately let a patient die who was suffering from a routinely curable illness, the doctor would certainly be to blame for what he had done, just as he would be to blame if he had needlessly killed the patient. Charges against him would then be appropriate. If so, it would be no defense at all for him to insist that he didn't 'do anything.' He would have done something very serious indeed, for he let his patient die.⁴ §

The intentionality or deliberateness of the "act of omission" is crucial; it is the goal-directedness of the omission and the foreknowledge of the results of the

‡ Our "vast ignorance about polygenic traits protects us against the main possibilities of harm [through genetic control of behavior and character] from gene replacements."³

§ See also Fletcher.⁵

omission that makes the omission an act for whose foreseeable consequences one is responsible.

On this view, then, the response to Ramsey would be that to deliberately refrain from acquiring the knowledge which would be sufficient to enable us to prevent or cure cases of genetic disease in the future would be to act so as to be responsible for those consequences (in that one chose to act in a manner that did not prevent what one could have prevented). One must, in other words, compare the foreseeable results of acting so as to acquire the knowledge with the foreseeable results of acting so as not to acquire it, for one is not in a context in which one is choosing between acting in some way and not acting at all. And when one does make this comparison with respect to learning how to avoid and cure genetic disease, the consequences of not learning how are clearly worse than those of learning how. (Put somewhat simplistically, it amounts to a calculation of the cost of acquiring the knowledge in terms of lives impaired or lost that would otherwise *not* have been impaired or lost, and comparing that with the lives not impaired or lost that otherwise *would* have been. It's "simply" a matter of numbers.)

On the other hand, some find the difference between a certain act and refraining from that act to be significant, on the grounds that in the former case one *causes* certain results whereas in the latter case the foreseen consequences aren't caused by one's refusal to act. Even if one accepts this view (together with the underlying view of causation), one still might want to divorce the question of the morality of acting or not acting from questions of causality. After all, there is a strong feeling that many people have, which is reflected in the law, that one is somehow responsible for deaths which could have been prevented by his or her action. That is, our concept of responsibility extends beyond that of events resulting from our actions to events which would not have occurred but for our deliberate inaction. Hence, by recognizing that the concept of responsibility extends to events which would not have come about but for one's deliberate inaction (where the event's preventability was known to the agent), we see that even if refraining from an action is not itself an action, we may not be excused from responsibility for events which we do not cause. Given this, it becomes appropriate to ask whether it is more responsible to act so as to prevent many occurrences of deadly or debilitating genetic disease even if to do so causes a relatively small number of such occurrences, or to act so as to avoid causing this small number at the expense of allowing the great number to happen. Put that way, the answer seems obvious. (Perhaps Hippocrates' maxim should have been "Permit no harm you can prevent.") If it is evident that, in the long run, far fewer cases of defective newborns will result from the development of the knowledge necessary to repair or avoid monogenic defects than from Ramsey's moratorium on such developments, and we may thereby more faithfully serve our macroethical maxim, our duty seems clearly to be to act so as to acquire this knowledge. Microethical considerations have their proper place within the context of those situations into which macroethical behavior leads us; they may be misapplied, however, when treated as absolutes against which macroethical behavior must be checked.

At the same time, it must be admitted that other problems exist in our pursuit of macroethical and microethical aims and directives. If we are to remain true to the humanistic individualism that has fostered molecular genetics and its application to *Homo sapiens*, these shortcomings must be faced and remedied. What follows is an incomplete list of such problem areas of human molecular genetics that require immediate and sustained attention.

(1) If one reflects on the individualistic, macroethical maxim "Act so as to maximize lifespan and reproducibility of all individuals", one is quickly led to see that great, unjust inequities exist in the distribution of health care across various levels of our society, particularly economic ones. The ethical maxim is *not* "Act so as to maximize the lifespan and reproducibility of all individuals who can afford the cost". An ethical law, like a scientific law, cannot be restricted to a particular segment of society or locale and remain an ethical law; the requirement of "generality" for ethical maxims is one point on which there has been general agreement among philosophers from Immanuel Kant⁶ to Richard M. Hare.⁷ Insofar as the private, fee-for-service system of health care distribution is one of the roots of such inequity, it must, as a macroethical requirement, be replaced or modified so as to bring our delivery of health care into accord with the values that have given impetus to its development. With respect to the development and application of human molecular genetics, we would again have a conflict between macroethical and microethical values if the experimental sacrifices for these advances were borne by one segment of society or of humanity, but the fruits were available only to another. The fruits of medicine's advances must be accessible to all of a potential subject pool as a precondition of that pool's legitimate eligibility.

(2) A second area of concern has to do with the tendency to identify various human disorders and undesirable conditions as genetic whenever evidence for there being a genetic component surfaces. Most, if not all, "genetic diseases" have nongenetic components as well; indeed, this is the basis for dietary, drug, surgical, and gene-product replacement therapies for such disorders as galactosemia and phenylketonuria, gout, pyloric stenosis, and type 2 glycogenosis.⁸ The tendency is to identify a partial cause of a complaint as the disease itself, and this can be particularly invidious when the environmental component is large and variable. Another case in point is found in a recent article reporting observations by Stanley Walzer and Park Gerald of Harvard Medical School that XYY chromosome pattern "is a 'disease,' ... and ... children who have it are entitled to medical treatment just as they would be for any other disease" — this despite their admission that "some XYY children are 'hard to handle' [while] others are 'perfectly fine.'"|| This is pernicious in that, by labeling the abnormality a genetic disease, not only has the concept become dissociated from the root notion of a patient's complaints (his or her "dis-ease"), but also it directs attention away from the question of what are the environmental conditions under which the abnormal complement of genes expresses itself; it invites us to view the individual's genotype as both the locus of responsibility for any behavioral difficulties and the proper stage for intervention. Labeling a disease as genetic exerts a powerful control over the direction of research and treatment; it should be obvious that, in terms of public and parental perceptions, values and taboos, there are also powerful effects of labeling a disease genetic and of labeling a genetic or chromosomal abnormality a

|| Reported by Barbara J. Culliton.⁹ In fairness, it should be pointed out that Gerald and Walzer are not arguing for a "criminal chromosome" interpretation of their data, and that other XYY researchers resist commitment to defining the aberration as a disease. Culliton quotes one such researcher anonymously as saying, "The reason we all need to continue our studies is to find that out." But it is not at all clear how any further empirical research will bear on the classification, since it is already known that not all who bear the abnormality have significant behavior problems.

disease on the very environment whose variables provide the context for genetic expression. The general point is that we may, in overzealous pursuit of the new advances in genetic technology that our macroethical imperative has stimulated, avoidably worsen the lot of those whom we incautiously label the genetically diseased, and thereby violate our microethical duty to "do no harm." At the least we need to develop a classificatory system for diseases that accurately reflects the relative degrees of contribution of genetic and nongenetic components.

(3) The final macroethical issue that I want to raise is the question of where lies the proper forum for policy decision in determining the directions and controls for developing molecular genetic research and directing the use of its discoveries. A recent article in the *U.S. News and World Report* (April 7, 1975) offered disturbing praise of the Asilomar Conference: "The Conference was a landmark because it provided for all scientists a working illustration of how specialists can examine and, when necessary, limit their research for the public good long before the issues are dragged into the obscuring atmosphere of the public arena." Such a comment reinforces a kind of elite paternalism that is common in scientific circles and that is predicated on the assumption that such a group of specialists is sufficiently representative and sufficiently wise in its deliberations to determine what is in the public good. It also presupposes that voluntary limitation of research under peer pressure is adequate to secure the public interest against the hazards being addressed. Both suppositions are questionable, and one wonders whether there is already a concrete cause for concern in the fact that the Asilomar resolution was not unanimously supported by the scientists assembled there. This is not a condemnation of the results of the conference but of the elitist, closed means by which they were attained, the rather naive presumptions under which they are to be implemented and enforced, and most of all the alleged ideal character of this kind of conference asserted in this sample of the lay press. If we are to remain true to our individualistic macroethic, we must recognize the right of the entire public to be, as Harold Green has put it, "fully and candidly" informed "as to where we now are and where we may be going in the future."¹⁰ Such information allows the public, as it does the patient and experimental subject, the opportunity to assess the risks and benefits involved and to decide whether to consent to or veto the proposed research.

But it is not just a question of the public's right to know, or even of its right to veto; it is a question of the public's right and duty to participate in research and its planning. Earlier in this conference, Robert Morison expressed skepticism about the value of the results of casual public involvement. Even if we grant this, it does not follow that we must adhere solely to elitist peer review, but rather that we must either do that or raise the level of education of the public by means of a long-term commitment to public involvement in research and the requisite means thereunto — a kind of coinvestigator role for representatives of the public (perhaps "graduates" of the Hastings Institute), similar to the coinvestigator model of the patient/physician and subject/experimenter relations described by Renée Fox¹¹ and others. For these issues and new techniques do involve the very essence of what it is to be human, and under our individualistic ethics, it is ultimately the right and responsibility of each individual human to determine that for himself or herself, in concert with his or her peers.

ACKNOWLEDGMENT

I wish to express appreciation to the State University of New York at Buffalo for support during the sabbatical leave year, when this paper was prepared.

REFERENCES

- MULLER, H. J. 1960. The radiation danger. *Col. Quart.* 6 (No. 3): 311-16.
Reproduced in Muller, H. J. 1973. *Man's Future Birthright*. E. A. Carlson, E.: 68-87. State University of New York Press. Albany, N.Y.
2. WILLIAMS, R. H., Ed. 1973. *To Live and To Die: When, Why and How*. Springer Verlag, New York, N.Y.
3. DAVIS, B. 1974. Genetic engineering: How great is the danger? *Science* 186: 309.
4. RACHELS, J. 1975. Active and passive euthanasia. *New England J. Med.* 292: 78-80.
5. FLETCHER, J. 1973. Ethics and euthanasia. *In Williams*²: 113-122.
6. KANT, I. 1948. *The Moral Law*. Translated by H. J. Paton. Barnes & Noble, Inc. New York, N.Y. (First published in German in 1785 under the title *Grundlegung zur Metaphysik der Sitten*.)
7. HARE, R. M. 1952. *The Language of Morals*. Oxford University Press. London, England.
8. FRIEDMAN, T. & R. ROBLIN. 1972. Gene therapy for human genetic disease? *Science* 175: 949-955.
9. CULLITON, B. J. 1974. Patients' rights: Harvard is site of battle over X and Y chromosomes. *Science* 186: 715-717.
10. GREEN, H. Mechanisms for public policy decision-making. *In Hilton et al.*^{1 2}: 385-394.
11. FOX, R. C. 1959. *Experiment Perilous*. The Free Press. Glencoe, Ill.
12. HILTON, B., D. CALLAHAN, M. HARRIS, P. CONDLIFFE & B. BERKLEY. 1973. *Ethical Issues in Human Genetics*. Plenum Press. New York, N.Y.

 DISCUSSION

DR. JOHN MONAGLE (*St. Vincent's Hospital, Toledo, Ohio*): I sense a certain elitism, even in philosophical discussion, in that somehow, in order to face the problem realistically, we have to adopt a consequentialist attitude. Does not knowing the specific consequences that can result from gene therapy or genetic manipulation mean that an agent must refrain from acting?

DR. HULL: There does seem to be a serious difficulty which any consequentialist utilitarian faces in passing judgment upon individuals who, for reasons of personal or religious persuasion, or perhaps well- or ill-considered prudence, decline to do what generally appears to be in the public interest. Paul Ramsey's position is a good case in point because he holds that even if the consequences of holding a moratorium on acquiring the knowledge necessary to alleviate man's genetic burden are the genetic apocalypse and the end of man, then it is more moral to do so than to impose upon particular individual human beings suffering that they otherwise would not have experienced.

DR. LAPÉ: Since so much of the discussion about the moral imperative for genetic intervention is contingent on genetic deterioration and an increase in

so-called genetic burden or genetic load, I wonder if anyone would like to address the factual question as to whether there is a demonstrable deterioration in the gene pool. Dr. Hull, would it make a difference to your arguments if there were no deterioration?

DR. HULL: It would not make a difference to my general position unless it could be shown that if we continued on without the development of certain genetic techniques, the incidence of genetic disease would decline as the result of some natural processes. Even if the incidence of genetic disease were to be stabilized, it is still more moral to take whatever steps are necessary to develop knowledge of genetic therapy than it is to refrain from developing it because the total amount of human suffering is less when genetic knowledge is extended.

DR. ROBLIN: I'd like to ask Richard Hull a question about increasing democratization, although perhaps it's wrong to ask a philosopher for practical solutions to questions like this. I am in sympathy with your point about increasing democratization of decision-making, but in my experience, one is always caught on the problem of exactly where to stop. For example, at Asilomar we invited a group of lawyers and they made a great contribution to the conference. But how many lawyers would have been enough? Would it have been better to have had some psychiatrists there as well? Who should we consult? Who is the relevant public in decision-making situations like this? We could envision a hypothetical situation where everyone in the world turns on his TV set which has a Yes/No button attached to it, and we settle everything by worldwide vote. At the other end of the spectrum are tiny groups of so-called elite experts making decisions that affect large numbers of people on the basis of their values and perceptions, which may or may not be correct. In practical terms can you suggest where we might strike the balance?

DR. HULL: There are certain requirements that we would want to make upon the individuals who enter into a more democratic decision-making body. One is that they be able to understand in a general way what they are being asked to decide about. Consequently they must have certain levels of basic conceptual familiarity with the type of research. Another requirement is that they be disinterested parties; that is, that they not have professional or financial interests in the conducting or halting of the particular research. If we just take those two criteria, we can characterize the kinds of individuals we would want to have join and participate in conferences, peer review boards, and in bodies that are deliberating the allocation of public funds for research.

The problem is how representative is representative enough, and I want to resist trying to answer that. Given public reception of these kinds of issues, and the tendency for the public to jump to science-fiction characterizations of the evils that lurk on the horizon, there needs to be a greater increase in public understanding as well as in public participation in the decision-making process.