

carry out hydrolysis of the polypeptide chain from tRNA in the absence of any release factor activity. This enzymatic site may therefore be involved in the normal mechanism of chain termination (14).

THOMAS CASKEY

Baylor College of Medicine,
Texas Medical Center, Houston 77025

PHILIP LEDER

National Institute of Child Health
and Human Development,
Bethesda, Maryland 20014

KIVIE MOLDAVE

Department of Biochemistry,
University of California,
School of Medicine, Irvine 92664

DAVID SCHLESSINGER

Department of Microbiology,
Washington University School of
Medicine, St. Louis, Missouri 63110

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14. The participants in the conference were J. Allende, W. Anderson, J. Bodley, L. Bosch, T. Caskey, M. Capecchi, W. Cohn, P. Condliffe, T. Conway, B. Davis, R. Gesteland, J. Gordon, F. Gros, B. Hardesty, M. Harris, S. Heywood, R. Kaempfer, A. Kaji, Y. Kaziro, P. Leder, P. Lengyel, F. Lipmann, H. Lodish, J. Lucas-Lenard, U. Maitra, K. Marcker, M. Mathews, E. Maxwell, K. Moldave, D. Morse, D. Nathans, H. Noll, S. Ochoa, A. Parmegiani, S. Pestka, A. Peterkofsky, M. Rabinovitz, J. Ravel, M. Revel, D. Schlessinger, T. Staehelin, R. Thach, A. Tissieres, D. Vazquez, H. Voorma, A. Wahba, S. Weiss, and H. Weissbach.

Ethics, Law, and Genetic Counseling

Genetic counseling has moved out of its childhood, into a period of fast-growing adolescence. Advances in genetic knowledge, increased public demand, and refinements in amniocentesis help account for the sudden spurt. But what are its goals, and what ought the means to be?

That was the general theme of an international conference on "Ethical Issues in Genetic Counseling and the Use of Genetic Knowledge," held at Airlie House, Warrenton, Virginia, 12 to 14 October 1971, where 85 participants from six countries met. The interdisciplinary conference, cosponsored by the Institute of Society, Ethics and the Life Sciences and the John E. Fogarty International Center, National Institutes of Health, sought to explore the ethical dilemmas of genetic counseling in their philosophical, scientific, legal, sociological, and political ramifications.

While one must expect arguments in a conference of this kind, the tenor was not that of unbridled disputation. Instead, it was one of serious perplexity and a recognition that the difficulty of the central questions sorely strains the limits of present knowledge, scientific technique, and cultural wisdom. This mood was exemplified in the opening

address, given by T. Sonneborn (University of Indiana). He noted that, while the conference brought together scientists and representatives of the humanities and social sciences, no simple polarity can be established between the two groups. The scientists disagree among themselves on the issues no less than the philosophers, lawyers, and social scientists. "Who or what decides what is right or good? By what authority? What do we really mean when we ask about anything: 'Is it ethical?'" On questions of this kind, Sonneborn noted, there is neither certainty nor uniformity of opinion. "Humility and compassion" are imperative in the face of ethical complexity, he said.

After Sonneborn's address, the conference moved systematically through a number of problems, beginning with a series of papers on the present scope of genetic counseling and the variety of dilemmas presented to the counselor. F. C. Fraser (McGill University) presented data to show that, in at least one large and perhaps not untypical counseling center, most of the problems presented (usually on referral) deal with the question "Will it happen again?"—that is, will there be a recurrence of some disease or defect already

known to exist in a family? The range of conditions presented is very wide, totaling 349 at the center analyzed by Fraser. Of that number, 61 were either sex-linked or diagnosable in utero, making the possibility of amniocentesis a relevant consideration. Accurate diagnosis, Fraser noted, is the first step in the counseling process, followed by a determination of the probability of recurrence, and concluding with assistance by the counselor in helping the family to reach a decision.

If it is often difficult for patients to know what to do, the pressures on the counselor are often no less. Sometimes the counselor is stymied by an inability legally to get pertinent data from hospital records. At other times, as M. W. Shaw (University of Texas) stressed, de facto and de jure obstacles stand in the way of options available to the counselor or to the family (for example, local antiabortion statutes). "The right of privacy," in particular, poses some acute dilemmas, a theme developed by both Shaw and H. A. Lubs (University of Colorado Medical Center). The law does not require an individual to make known the fact (if he has discovered it) that he harbors a deleterious gene; nor does it require that a physician inform other family members. But should it? Lubs presented a number of case histories to show how painful the dilemmas of privacy can be even at present; and they may increase as nationwide genetic data banks are established.

Another cluster of dilemmas facing the counselor turns on different theories and styles of counseling individual patients. J. Hall (Johns Hopkins Hospital) noted that the traditional role of the counselor has been that of "neutral educator," essentially doing no more than presenting patients the odds and the facts. But this concept faces increasingly heavy weather, particularly because of the rapidly expanding range of options. Not surprisingly, these developments have led to disagreements among counselors about the kind of stance they should take toward their patients. J. R. Sorenson (Princeton University), in a sociological survey of decision-making in counseling practice, noted that, however much the value of neutrality on the part of the counselor may be espoused, counselors do in fact often make decisions for their patients, or at least heavily influence the decisions by the way they present data. J. Fletcher (Ecumenical Training Center) came to a similar conclusion in his findings on

the actual practices of counselors when their interactions with patients are carefully observed.

These dilemmas are not likely to disappear in the near future. As J. W. Littlefield (Massachusetts General Hospital) noted in a paper on the status and problems of amniocentesis and prenatal diagnosis, the number of inherited metabolic disorders presently or potentially diagnosable in utero continues to grow. More individuals will be determined to be at risk for genetic disease, and more fetuses will be diagnosed as defective. What, then, should the response of society be to genetic disease and defect?

A. Motulsky (University of Washington), in a paper on the significance of genetic disease from a patient perspective, developed the point that the concept of "normal" and "abnormal" is statistical rather than philosophical, and that even with given defects (such as Down's syndrome) the range of variation in expression can be wide. J. F. Crow (University of Wisconsin Medical School) contended that, from the perspective of population genetics, the minute number of individuals receiving genetic counseling makes the statistical impact negligible. However, assuming an increase in genetic counseling and knowledge, Crow also argued that we are not nearly so ignorant of long-range possibilities as many would contend. In particular, it is possible to predict relaxed natural selection, comparatively little gain to selection even with abortion of all fetuses carrying one or more mutant genes, only a 50 percent change in traits even with full reproductive compensation, and an increasingly important role for mutation as a component of genetic disease. Crow's key point was that, in dilemmas pitting individual welfare against the genetic welfare of the species, it is still reasonable to give the benefit of doubt to individuals.

The Motulsky and Crow papers led the conference into discussion of the deepest and most troubled ethical issues. D. Callahan (Institute of Society, Ethics and the Life Sciences) considered the significance of genetic disease from a philosophical perspective. He observed that society has taken many centuries to develop a sensitive, receptive response to the defective person; that gain should not be jeopardized by new-found powers to ameliorate defectiveness. D. Brock (Edinburgh University, Scotland) pointed out that words such as "abolish," "eliminate," "eradicate," and

"conquer," when used with respect to genetic disease, carry with them the danger of apocalyptic visions and correspondingly coercive, draconian solutions—approaches incompatible with the need to develop genetic counseling "as an expression of man's humanity to man."

The question of what it means for human beings to treat each other humanely was at the center of the papers specifically devoted to ethical issues. J. Gustafson (Yale University), in an "ethical overview," urged that while a pluralism of values in our society makes a consensus on particular ethical issues unlikely, it might be possible (and highly desirable) to reach some minimal social agreement on at least what consequences should be avoided in the development of genetic counseling and the use of genetic knowledge. (The papers and resulting discussion at the conference suggested, for instance, a strong consensus against coercive strategies.) Robert F. Murray, Jr. (Howard University Medical School) contended that, even in mass screening programs, the welfare and freedom of individuals or couples should always come first. A similar note was struck by M. Kaback (Johns Hopkins Medical School) in his description of the goals of a large Tay-Sachs screening program in the Baltimore area. Indeed, Murray and Kaback agreed that it is probably unethical to even mount screening programs unless there exist specific therapeutic alternatives for patients and carriers.

P. Ramsey (Princeton University) pressed the ethical issues still further, arguing that care must be taken, particularly in the techniques of prenatal diagnosis, not to infringe the minimal ethic of medicine, "do no harm." Moreover, if this principle is taken seriously, it should include a consideration of the fetus as well as that of the mother. The ethical principle of the "greatest good to the greatest number," which many use as their fundamental ethical axiom, has a major drawback. It does not allow one to compare the depth of harm to a few with the breadth of benefits to the many; thus a critical ethical dilemma is ignored.

At the heart of the sessions devoted to ethical issues were three papers on "the right of life," by H. D. Aiken (Brandeis University), L. R. Kass (National Academy of Sciences), and R. S. Morison (Cornell University). Aiken developed a philosophical argument to show that no right could be absolute, including the right to life. Moreover, he

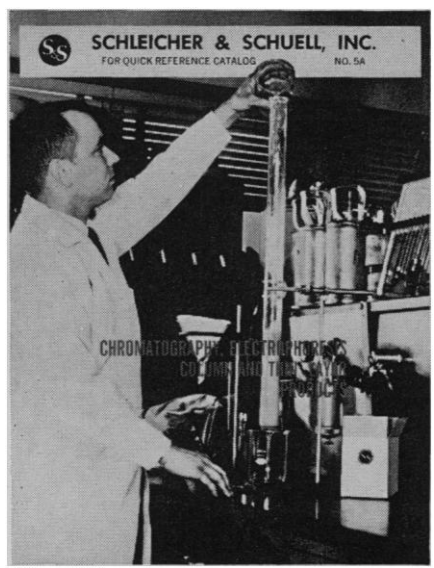
held, any judgment concerning the right to life of an individual must be judged in the context of the possibility of that individual's being able to exercise a wide range of other rights. In the absence of that latter possibility, the right to life becomes empty and may be set aside.

Kass centered his discussion on the ethical issues raised by abortion of "defective" fetuses. The central question, as he phrased it, turns on the belief in the radical equality of all human beings, defective or not, an equality which presumes certain fundamental rights, including the right to life. The very language often used in talking about defectives may be prejudicing individual cases—for instance, when one says "the fetus is a Down's" rather than "the fetus has Down's syndrome." Dangerous and dehumanizing attitudes can easily develop. Kass's line of argument laid heavy stress on the need to develop or to recognize a "natural standard" for making ethical decisions. R. S. Morison countered by pointing out the primacy of society's interest in the quantity and quality of the children who are, or will be, born. Moreover, the use of society as a standard, instead of a natural standard, by no means entails a descent to totalitarianism or brute coercion.

These papers formed the backdrop for the ensuing papers on law and public policy. The Honorable Lord Kilbrandon (Scottish Law Commission) presented a rich sketch of the comparative laws of different nations as they apply to genetic counseling and related issues. C. Fried (Harvard Law School), in a response to Lord Kilbrandon's paper, pointed out the need for a philosophical anthropology which would better enable the public, professionals, and legislatures to deal more adequately with the complicated questions of rights and obligations being raised by advances in the "new biology." A. Capron (Yale Law School) developed the position that, while parents have a legal right to be fully informed decision-makers about whether to have a child, this right operates in the counseling situation independently of any moral conclusions. In addition, Capron argued that there is no necessary connection between legal and moral rights. A defective child, for instance, may have a moral claim against its parents for bringing it into the world; but, Capron argued, such a claim would be much too far-reaching if made a legal rule.

The final set of papers dealt with the establishment of social and scientific

new



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priorities and with the development of mechanisms for public policy decision-making. J. V. Neel (University of Michigan Medical School), after sketching a number of present and potential genetic developments, presented four possible criteria for setting priorities: reduction of the proportion of persons with genetic disease, improvement of the expression of existing genotypes, creation of genetically superior individuals, and protection of the present gene pool by a world population policy. His conclusion is that we are not yet scientifically, ethically, or socially in a solid enough position to make wise choices among the possible priorities.

The conditions for achieving the necessary kind of consensus for deciding on priorities and for public policy-making were analyzed by D. A. Kindig and V. W. Sidel (Montefiore Hospital; Einstein College of Medicine) and by H. P. Green (George Washington University Law School). The former paper pressed for a more complete relating of genetic problems to other social issues and priorities in society. The need for better social and political processes to carry this out is evident, they said. Kindig and Sidel agreed with Green that decisions in this area must be made by an informed public and not by elite groups. This point was underscored by D. Eaton (All Soul's Unitarian Church, Washington, D.C.), who noted that genetic disease is a much greater preoccupation with whites than with blacks. In addition, Green contended that, if the public is to have genuine options and to become fully informed, there must be public debate and a resort to the adversary system. This method does not always guarantee truth or wisdom, but it does facilitate open discussion, a minimum necessity for wise public decision-making. K. Ludmerer (Johns Hopkins Medical School) stressed, in this context, the importance of public education for an understanding of the capabilities as well as limitations of science.

Where is the future likely to take us in genetics? This question, which kept surfacing throughout the conference, was directly confronted by R. L. Sinsheimer (California Institute of Technology), who asked whether future scientific developments are an "ambush or opportunity"? His clear answer was "opportunity," even if laced with dangers. Higher states are possible for the human species, intellectual, emotional, and moral; the price of not pursuing them would be "to stagnate in fear and

doubt." J. V. Neel responded from the floor that he did not agree with Sinsheimer's thesis. Others agreed in part and objected in part. That typified the entire conference.

D. CALLAHAN

*Institute of Society, Ethics
and the Life Sciences,
Hastings-on-Hudson, New York 10706*

Forthcoming Events

April

20-21. **Cooperative Education**, 1st natl. conf., Newton, Mass. (M. B. Zerwick, Commco PR Inc., 310 Madison Ave., New York 10017)

21-22. **New Mexico Acad. of Science**, Socorro. (Miss L. M. Shields, New Mexico Highlands Univ., Las Vegas 87001)

24-27. **American Physical Soc.**, Washington, D.C. (W. W. Havens, Jr., APS, 335 E. 45 St., New York 10017)

24-28. **Inter-American Congr. of Cardiology**, San Francisco, Calif. (A. M. Bennett, American Heart Assoc., 44 E. 23 St., New York 10019)

24-28. **Structural Engineering—An Overview for the Seventies**, American Soc. of Civil Engineers, Cleveland, Ohio. (H. Hands, ASCE, 345 E. 47 St., New York 10017)

24-29. **American Acad. of Neurology**, Palm Beach, Fla. (S. A. Nelson, AAN, 4005 W. 65 St., Minneapolis, Minn. 55435)

24-6. **Psychotherapy Week**, 22nd, Assoc. for Psychotherapeutic Training, Lindau, Germany. (H. Stolze, Lindauer Psychotherapiewochen, Adalbert-Stifterstrasse 31, D-8 Munchen 81, Germany)

25-26. **Scanning Electron Microscope Symp.**, 5th annual, Chicago, Ill. (O. Johari, IIT Research Inst., 10 W. 35 St., Chicago 60616)

25-28. **Significance of Insect and Mite Nutrition**, Lexington, Ky. (J. G. Rodriguez, Dept. of Entomology, College of Agriculture, Univ. of Kentucky, Lexington 40506)

26-28. **Biometric Soc.**, Eastern North American regional, Ames, Iowa. (F. B. Cady, Jr., Biometric Unit, 337 Warren Hall, Cornell Univ., Ithaca, N.Y. 14850)

26-28. **Operations Research Soc. of America**, New Orleans, La. (R. M. Oliver, Operations Research Center, Univ. of California, Berkeley 94720)

27-29. **Eastern Psychological Assoc.**, Boston, Mass. (W. W. Cumming, 353 Schermerhorn Hall, Columbia Univ., New York 10027)

27-29. **Red Cell Metabolism and Function**, 2nd intern. conf., Ann Arbor, Mich. (G. F. Brewer, Dept of Human Genetics, Univ. of Michigan, Ann Arbor 48104)

27-30. **Association of Clinical Scientists**, Elkhart, Ind. (F. W. Sunderman, Jr., Drawer B, Newington, Conn. 06111)

28. **Georgia Acad. of Science**, Athens. (E. A. Stanley, Dept. of Geology, Univ. of Georgia, Athens 30601)

28-29. **Indiana Acad. of Science**, Notre

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