

Scientist's responsibility

Norio FUJIKI

The application of new biotechnology has developed in the tremendous speed and DNA technology has created ethical problems needing some guidelines on the medical genetic practices in mass screening, prenatal diagnosis and carrier detection of genetic diseases, as well as in prediction for gene combinations or susceptibility for common diseases. I, as President of the International Association of Human Biologists (I.A.H.B.), would like to report the bioethical aspects of medical genetics, especially on human genome research, which become more and more important in our societal lives.

Bioethics concerns not only problems of birth and death, but also what we will pass on in the inheritance to next generation. Therefore, this time, we attempt to confine the themes to issues concerned with medical genetics. On summary, we emphasize internationally on moral norms, not specifically concerning with how we, human being, should survive in this period of rapid technological developments, but rather concerning the multidisciplinary processes not only within but also between the specified areas of biology and medicine, with such allied fields of as philosophy, sociology, psychology, law and economics.

In Japan, there have still immature developments, but Japan Society of Bioethics (J.S.B.) has commenced its activities 3 years ago, and had over 10 international conferences on dialogue on bioethics. Among them, I have as medical geneticists, participated with 1987 Bioethics Seminar in Fukui, I.A.H.B-J.S.H.G 1990 International Panel Discussion on Ethics in Medical Genetics in Fukui as well as Council for International Organizations of Medical Sciences (C.I.O.M.S) Conference on Genetics, Ethics and Human Values in Tokyo and Inuyama in 1990.

From the standpoints of medical genetics, the existence of eugenic movements must be taken into considerations. There have has recent examples, in which arising problems from screening or testing have sometimes achieved unintended or unwanted outcomes : the involvement of human geneticists and psychiatrists in the crimes committed in Nazi Germany, has been a taboo for several decades, appeared to be nightmare, and many scientists could get out from this nightmare only to plunge into the deep sleep of amnesia. And more recently, we have also has the unpleasant experience for the leakage of such genetic information as sickle cell anemia at the mass screening survey and the disturbance of employment and insurance of the patients themselves. Nobody could imagine the fear of nuclear contaminations, when famous physicist has discovered the nuclear reaction, which was at that time thought as wonderful with surgeon for the withholding the heart operation of the infants with Down syndrome. Not only myself but also many physicians have been taught from severe handicapped infants, the facts that even physically or mentally handicapped have had respectful human dignity, which have never spoiled.

In recognition of the urgent problems resulting from the rapid developments of sciences and technology and in order to both explore common areas and attempts to bridge the cultural differences between the East and West, we have has 1987 Bioethics Seminar in Fukui, with over 180 Japanese participants and 5 foreign scientists, including Professor Jean Bernard. Among many issues confronting us, there were the applications for early genetic diagnosis, mass screening, prenatal diagnosis and carrier detection in genetic counselling, as well as the clarifications of the quality of life and euthanasia, cancer, diagnosis, organ transplantation and brain death, and published the book *«Human dignity and medicine»*.

Although recent studies on mapping and sequencing of human genome lead

to the detection and diagnosis of genetic diseases, the long range goal goes beyond this to providing improved treatment, prevention and ultimately cure. The interim phase is the one in which the most deleterious consequences can occur, as below-mentioned as discrimination against gene carriers, loss of employment or insurance, and also stigmatization, ostracism, labelling, individual psychological response including impact of self-image. These reflexions lead to the following questions :

- 1) is the work with human genome potentially violating the dignity of human ?
- 2) is the information emerging from this research potentially dangerous ?
- 3) how should we judge the possibility of the abuses of such informations ?
- 4) do we have a particular responsibility in this debate that goes beyond the obligation of all informed citizens ?

A consequence of these reflections would be to following propositions :

- 1) the carrier of a genome has the exclusive right to knowledges of his genotype. Carrier should never be confronted with knowldges they did not ask for.
- 2) employers, insurance companies or agencies of the government should have no right to information about the genotype of employees and clients
- 3) to ask for prenatal diagnosis and selective abortion has to be the exclusive right of the pregnant woman. Pro-choice is a part of this process and should be defended.
- 4) sick carriers of genetic diseases should have equal rights to insurance and medical help, as also stated in Inuyama Declaration of C.I.O.M.S Conference.

A declaration of the scientific community on these points is needed. Hence, we as scientists, have ought to have responsibility for our society, such as telling truth, giving informed consents with confidentiality and autonomic decision makind, resluted into establishment of good patient-doctor and client-councillor relationship, leading to the justification of the prevention and treatment in the question, although we have emphasized these responsibilities in our edited book «*Hand Book of Genetic Counselling*», sponsored by Ministry of Health and Welfare Japan in 1983.

We are making every effort for early diagnosis, treatment and prevention of hereditary diseases, using the genetic ocunselling techniques, although it is rather

small contributions for our preventive measures. The early even pre-emptomatic diagnosis in Huntington chorea and carrier detection in thalassemia, and also such genetic susceptibility of common diseases, as Apo protein as a marker for hyperlipoproteinemia in coronary heart disease, would now discuss in ethical standpoint. At 1990 C.I.O.M.S Conference on Genetics, Ethics and Human Values in Tokyo and Inuyama and I.A.H.B.-J.S.H.G. 1990 International Panel Discussion on Ethics and Education in Medical Genetics, for which we have published the book *«Medical Genetics and Society»*, we have concluded there have been so many prejudices and misunderstandings on heredity and handicapped, after our follow-up study of over 3000 genetic counselling cases for 35 years and consensus survey in 2000 public cases. Therefore, new bioethical problems, as the justification of pre-symptomatic gene diagnosis for Huntington's chorea, and the possibility for the discrimination of patients with adult diseases and psychiatric diseases, using predictive markers, as well as the availability of impairment of health welfare for the handicapped children by these misunderstanding and prejudices, should be further discussed.

Here, an essential distinction must be made between the gene therapy of patients and the hereditary modification of the genetic information of mankind. Indeed, if a gene should be introduced in a somatic cell of patients, it could correct the diseases, but would not be inherited. Such a treatment could be compared to simple graft, such as bone marrow transplantation. Considerable efforts are currently being made to develop this perfectly ethical therapeutic approaches, the only hope for many patients and their families. But this contrasts with the modification of genes in germ cell or a early embryo, which means modification of the genes in next several generations. Fortunately, until now, all the scientific bodies have prohibited the insertions of foreign genes into human germs cells. In the future, if progress gives us the freedom to help families hosting a deleterious gene, perhaps this could be acceptable but only with the agreements of the highest international ethical and scientific authorities, and only after a large public debates based on complete objective and intelligible informations showing full with consensus among the human communities. Such a decision, so heavy with consequences could be only taken after a deep reflection, weighing its advantages and inconveniences. As long as the dangers would not be circumscribed and the risks limited, it appears to be unwise to open such a Pandora box as deteriorations of biosphere and mankind through the abuses of highly developed biotechnology.

This is the reason why the Universal Movement for Scientific Responsibility (MURS), a movement with no political, ethical and religious links, has undertaken an important initiative by professor Jean Dausset, Nobel Laureate, to propose an additional article to the Universal Declaration of Human Rights, concerning science and technology, and to address the universal consciences and obtain the solemn declaration endorsed by the most competent scientific bodies and in particular by the scientific academies.

From these considerations, we should provide the knowledges of science and technology, in order to protect the future biosphere and human dignity, equally for the global scales, not only for developed but also developing countries. This is our proposal on scientist's responsibility for this whole human species and environments. Medical genetics is the science itself for the study of individuality and variability, that all DNA sequences of each person have greatly varied, has important roles for the evolutionary process of human species, respecting the human dignity. If someone want to unify to some combinations of genotypes, which is regarded at present time as the most suitable for the present evaluation, the human species would disappear before 100 years. Thus, such great variability must be respected, in order to preserve the dignity of mankind.

In order to educate general public for their understandings on individual and social problems, we should remove the boundaries between the developed and developing countries, the professional and non-professional fields, and emphasize the more time for medical and postgraduate curriculum for medical genetics with bioethics for the scientist's responsibility in our own society.

Finally, we, with M.U.R.S, agree to add new article to the United Nations Universal Declaration of Human Rights, *«our scientific knowledges should be used only to promote the human dignity and preserve the integrity of scientific knowledges»* and close this message by the Spinoza's ethica : *«the souls of men are not conquered by arm, but only by love and generosity»*.

Norio FUJIKI
Professor, President of International
Association of Human Biologists