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The Genome Project and Pandora's Box

— The Light and Dark of Genetic Research —

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[keywords] genetic determinism, human dignity, right not to know

[abstract] In this article, while summarizing all the main problems involved in recent results of genetic science, I would first like to look into the topics that have social-ethical meanings. Then, as recent public interest and professional discussion have made implicit, I'll address questions of genetic determinism or reductive essentialism and focus on the complexity of the genes as an open system together with various other environmental factors. Furthermore values such as the sanctity of life and human dignity that have been the main supporting pillars in the ethical discussion about the negative aspects of genetic research, are not very clear ideas themselves in meaning and they will need to be relatively balanced with other values too. Then I'll focus on the very present desperate problem, which is that because of the gap in development between the genetic diagnosis and the genetic treatment, we can not help requesting *the right not to know* as well as *the right to know* about our own genetic information.

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Introduction

In Greek mythology, Pandora was a woman blessed by the gods with unsurpassed beauty, who was then sent into this world with a box in which all the vices of human torment were sealed. As the gods had expected, when she opened the box, all the various vices escaped from it and threw the world in a state of permanent suffering. However, other story tells us that various virtues also sealed and virtues had slipped away, there was just one remaining in the box and that was called 'Hope.'

Right now, in my opinion, the genome project for studying human genes is very similar to the opening of Pandora's box that released the sum of humanity's vices and virtues into the world. It is characterised both by positive light and at the same time dark shadow and moreover contains an element of nameless hope.

What will be the result of the genome project? Will it be hope or anxiety? Those scientists who have been participating in the project already recognize these two faces. Dr Watson, who helped to find the double helix structure of DNA and won the Nobel Prize for Physiological Medicine in 1962, was appointed the head of the entire human genome project in 1988. Dr Watson with

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his superb organizing talent and leadership has put this project on the main road. But from the beginning, he worried about the potentially negative impact of this project. He made a clear statement in a press conference at the time that he would dedicate part of the project funding to studying the social effects of genome research. One of the results is the ELSI (Ethics, Law, Society Interrelations) Program that is supported by the Energy Department and National Health Institute of America. As is clear from the name, ELSI is a project which will investigate the negative problems that can result from the human genome project.¹⁾

The 29th General Assembly of UNESCO held in Paris in 1997 made a universal declaration about the human genome and human rights with the unanimous agreement of the 186 member countries. In this declaration it was made clear that genetic research cannot take priority over human dignity and human rights. From that moment the social implications of the genome project began to be seriously discussed. But research and declarations on their own cannot stop or resolve the negative aspects of the project. Practical limits and methods used in the project must be put under *social control* for the kinds of decisions and choices which can be made through the proper care and participation of society's members.²⁾

1) 미리 보는 새 천년, 달라지는 삶 , 인간게놈 프로젝트 <2>, <동아일보> (2000.1.6).

Nowadays many NGOs (non-governmental organizations) throughout the world are strongly against the birth of designer babies and genetic licenses and have formed a powerful group through mutual solidarity. In some countries there are laws preventing the dissemination of genetic information for use either in insurance or matters of employment. After all it is up to us as humans to decide whether to use the results of the human genome project for our own good or ill. We are at a turning point between hope and anxiety. We all have to participate in the work in order to decide our own fate. This means that we have to share information, and at the same time, work toward a collective opinion through rational discussion, so that, together, we can take responsibility for the direction we choose to take.³⁾

In this article, while summarizing all the main problems involved in recent results of genetic science, I would first like to look into the topics that have social-ethical meanings. Then, as recent public interest and professional discussion have made implicit, I'll address questions of genetic determinism or reductive essentialism and focus on the complexity of the genes as an open system together with various other environmental factors. Furthermore values such as the sanctity of life and human dignity that have

2) <동아일보>, 앞의 글.

3) 황경식 『‘생명공학의 미래와 사회적 통제’ 철학, 구름에서 내려와서』, 동아일보사, 2001.

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been the main supporting pillars in the ethical discussion about the negative aspects of genetic research, are not very clear ideas themselves in meaning and they will need to be relatively balanced with other values too. Then I'll focus on the very present desperate problem, which is that because of the gap in development between the genetic diagnosis and the genetic treatment, we can not help requesting *the right not to know* as well as *the right to know* about our own genetic information.

I . The achievement and the present task of genetic science

Recent developments in genetic science, genetics for medical diagnosis and the associated therapeutic technologies that have followed as a result have produced huge expectations and promises about the prevention of genetic diseases and the possible methods of treatment. However, genetic science is still in a very premature stage of obtaining raw information about the genotypes and expressed types, and there are also various uncertainties about the practical application of genetic technologies in human life.

A fair amount of evidence has been that a certain definite and linear cause and effect model is in fact not

suitable for explaining the complexity and flexibility of human genes. Due to the hugely excessive expectations caused by those promises of genetic technology and a lack of general public understanding, the problem of ethical public policies related to the use of genetic knowledge has become that much more important.

The use of genetic information is traditionally broken down into four main topics. The first concerns the state of current knowledge itself about human genes, to make absolutely clear what we really know about the physiology of human genes. The second topic concerns the kind of problems that will be confronted if we continue to use genetic information, treat diseases and maintain our health in this way.

The third topic addresses the proper ways for us to deal with the main differences between humans, that is to say the differences of not only individuals but also cultures, races, sexes and religions and to respect them when we're applying genetics to human problems.⁴⁾

Finally the fourth topic, which is a priority among those tasked with forming legal or public policy deals with the misuse or overuse of information derived from human genes.

When those above-mentioned topics about the use of

4) Genetic Information, 'Caution, Cooperation, and Human Values, Genetic Knowledge, *Human Values & Responsibility*', Jacquelyn Ann K. Kegley Paragon House (1998).

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genetic information are discussed in their various aspects, there appears a series of common problems which I outline here below. The first problem can be called a problem of complication or complexity. Human genes are a very open and highly mutually functional system. So there is complexity and uncertainty at the various levels of a gene's functions or its expressions. Also, at present or even in the near future, it is expected that there will be many aspects that cannot be understood in human genetic physiology.

When we admit those characteristics like complexity and uncertainty of human genes, we can't avoid the second topic which advises that high caution and prudence are demanded in any attempts to apply genetic information in applications like getting rid of human diseases, maintaining our health and solving other human problems. Concerning the use of genetic information, the virtue of modesty based on admitting our ignorance cannot be over emphasized.⁵⁾

Being related to the second topic, the third topic, of the need for interdisciplinary research or cooperative scientific effort, is considered. Considering the vast amount of genetic information that the human genome project presents, there has to be a new effort toward a more integrated biological research at the molecular, cytological, organic and collective levels. The integrated scientific effort is directed at a common purpose, which is to establish a more inclusive

5) Jacquelyn Ann K. Kegley, *Ibid.*, p.3.

information base in order to fulfil the genetic medical examinations and treatments with more responsibility.

The third topic follows the integrated biological research for establishing a more inclusive information base with an integrated research into the social effects of genetic research. Due to those characteristics like complexity, uncertainty, probability and its massive power to influence humanity's substantial identity and welfare, the integrated research, while providing as many choices as possible and methods for coping with the genetic problems of individuals or families through academic research between biologists, psychologists, social-scientists, physicians, medical professionals and ethicists working in humanistic genetic services, must not lose sight of the purpose, which is to respect human dignity and human rights.⁶⁾

The fourth topic is related to professional individual responsibility. Scientists, health professionals, ethicists, law professionals and public policy professionals must do their best through cooperative effort to be responsible for preventing those various dangers which can be caused by the misuse of genetics due to wrong information and technology. One example of wrong information about genetics is the myth of *genetic essentialism*, which says that all explanations are ultimately genetic explanations. Also *genetic determinism*, the idea that everything is

6) Jacquelyn Ann K. Kegley, *Ibid.*

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pre-destined genetically, is another example of wrong information that has to be guarded against.

An example of wrong information in other areas is another that genetic solutions exist for non health related human difficulties like violence. As for another problematic area, genetic examination can produce wrong results and so lead to vices. In addition various problems can be induced by lack of resources for medical treatment. Furthermore the results of genetic examination can be used for human discrimination, stigmatising or sullyng a person's reputation. In order to prevent the above-mentioned problems, the professionals in every area need to take proper responsibility.⁷⁾

The fifth topic is that there is a considerable *gap* between medical diagnosis and medical treatment. So it's highly difficult to deal with diseases like Huntington's or Alzheimer's, which can occur later in life. Therefore the right not to know as well as the right to know has to be guaranteed as much as possible as allowed by the situation. Genetic professionals and healthcare professionals have to be morally responsible educators who can guide each individual through the decision in a moral, information-based way, and help others to deal with that information in various areas where individuals and families are going to be using genetic information in their own decision-making.

7) Jacquelyn Ann K. Kegley, *Ibid.*, p.4.

The sixth topic is related to the cultural, social, racial and religious contexts where those genetic opinion-decisions and human dealings are occurring. Different cultures can raise different values and ideas like disease and health, detriment and advantage when they are related to genetic problems or the use of genetic information. The differences must be understood and respected, in case there is an important effect to each individual's detriment or advantage. Of course, when such a difference brings substantial detriment to the individual, the use of genetics has to be refused or changed, but at the same time individual differences must not be over exaggerated, even though there is a cultural difference between individual rights and community. The similarity of value system also has to be emphasized. In any cultural areas, autonomy (self-control), justice and human rights must be respected and genetic information has to be used with responsibility for the benefit of humanity while differences and similarities are both properly respected.⁸⁾

II. Complexity of genes and genetic determinism

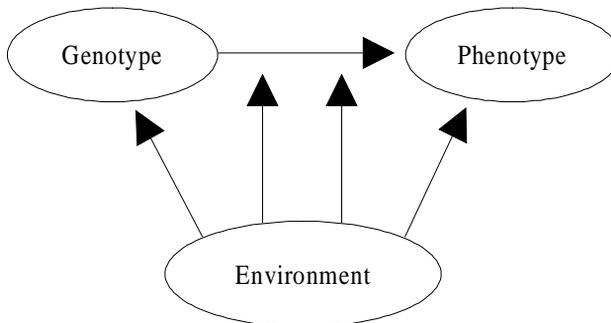
When we use genetic knowledge for dealing with human genes, particularly with human genetic diseases and defects,

8) Jacquelyn Ann K. Kegley, *Ibid.*, p.5.

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what we have to consider are various complications and complexities that are related to the structure and function of genes and genetic physiology. At the most basic level, we have to make a distinction between a hereditary body i.e. **genotype** which is the sum of genetic information and hereditary characters of that body, and **phenotype** which is the aggregation of confirmable characteristics of multiple organic bodies in different developing stages or different physical states and the aggregation of their hereditary diseases.⁹⁾

Furthermore organic bodies are regarded as a genetic system that has an incredibly dynamic interaction with environmental factors and this can be shown as a diagram (see below).



It is true that genes have a linear tendency in the

9) <The Human Genome>, 'Facts, Enigma and Complexities', Guido Pincheira, *Genetic Knowledge*, p.9.

chromosome and there are relatively exact relationships and gaps between each gene. However it is also true that many genes are partly overlapped with each other. Moreover, the reason it is such a complicated task to identify genes shown on a human genome is the variety of genetic functions and the variety of relations and interactions between parts of genes or other genes or environmental factors. Furthermore a human genetic body is an *open system* that interacts very abundantly and variously with environment. By obtaining a new constituent element or losing it through interaction it reconstructs or reforms itself and also by inducing qualitative or quantitative mutation into other cells, it offers a foundation for the thought that human genetic body is a real hereditary mosaic.

Due to the above-mentioned complexity and uncertainty caused by various interactions between the human genome, the environment and genes, we can't but pay huge attention when genetic knowledge is used in the treatment of human hereditary disease. After all, the potential for genetic medical treatment is extremely uncertain at the present stage of genetic knowledge. The success of genetic treatment depends on whether the difficult procedure to insert a new gene accurately into the genetic host can be done and whether the newly implanted genes are properly expressed in new circumstances.¹⁰⁾

10) Guido Pincheira, *Ibid.*, pp.19- 20.

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It can be said that medical treatment for a disease caused by a single gene is standing on fairly solid ground. But in the case of disease caused by multiple genes, not only accurate implantation and proper expression of genes, but also accurate arrangement, expression and adjustment of implanted gene with other genes is demanded. This can be said to be multiple tasks dealing with the multi-layered structure of human genetic body. At present our knowledge about genetic function, genetic expression and adjustment is still very limited, so our expectations and hopes about the genome project, can be overly optimistic.

We think it right to restrain scientific arrogance so it is important to keep a balance between scientific realism and individual optimism. It's not necessary to hold back the intellectual curiosity of scientists and their continuous effort for the development of knowledge, but it is necessary to position scientific results properly within a humanistic and moral frame. Also we all must strive to let humans benefit from the application of knowledge without unnecessary detriment.

Now what we have to be really careful of here is the formula of single linear uniqueness which the human genome project has as a premise. It is a formula that *unique effects* come from *unique genes*. (unique genes → unique effects). This means a certain particular disease comes from a certain particular gene. But this formula has

been questioned by experimental biology at all levels. Recent research achievement rejects *genetic determinism* as the main paradigm of modern biology in the modern age.¹¹⁾

Scientists are wrestling with the obvious limit of *genetic reductionism* and trying to reconstruct the genetic mechanism in a much broader interrelation of ‘*decision-making*’ in cells and organic bodies. This kind of interrelation is sometimes regarded as being restricted by *non-linear dynamics* or *chaos theory* but it is also described as *epigenetic regulation*, which is the more traditional name.

Now the point of this discussion is the fact that even though the tendency of basic biological research is moving from single linear genetic determinism to non-singular linear complexity, applied biomedical technology is still stuck in an outdated struggle without taking note of the fundamental changes brought about and emphasized by this experimental research. So a gap between basic biology and applied biology has come to appear and this gap will also pose dangers to our public health.¹²⁾

The main assumption by the modern trend of bio-medical thought is that genetic inheritance is the only inheritance. Biologists have always known that it is an imperfect

11) <The Nature of Polygenic Diseases>, ‘Toward a Holistic Theory of Biology’, R.C. Strohmman, *Genetic Knowledge*, pp.23-24.

12) R.C. Strohmman, *Ibid.*, p.24.

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opinion and recently established that the character of the paradigm itself was a much over-simplified one. In modern developmental biology the concept “*program as scripts for phenotype*” is being given up. There is no *isomorphic mapping* between Mendel's factor and a complicated phenotype. The mechanism of how an organic body can cause variations of the phenotype through the same gene or a genetically similar situation remains a profound mystery.¹³⁾

So in referring to the assumption of *gene programming*, serious matters need to be questioned. Firstly there appears to be less of an interrelation between genetic complexity and morphological complexity as we have presumed. A second question is that if programming does not occur in the gene, but the organic body is still demonstrably programmed, where is the program?

Apart from these questions, it is quite surprising that many of those arguments that see genetic engineering from a negative viewpoint are based implicitly on genetic determinism. Referring to this, it is very interesting to examine Dan Brock's two representative arguments, which say that human cloning itself is *intrinsically wrong* and cannot be permitted morally. One argument is based on *the right of a person to be a unique individual* genetically and another one is based on the thought that humanity has *the right to a future that is open*.¹⁴⁾

13) R.C. Strohmman, *Ibid.*, p.33.

The first argument, based on the general belief that an individual with a unique characteristic is important, implies a concept that cloning harms individual uniqueness. But it is based on the implicit proposition that says that two genetically identical humans lead identical lives by the law of deterministic cause and effect. But as research into identical twins shows, it is difficult to prove that a human clone lives the same life in terms of quality as the originally cloned human. According to statistics, even identical twins don't share more than 50% of characteristics. Furthermore, the similarity of human clones that have grown up at different times and in different circumstances can be expected to be even less than identical twins, so the power of this argument is decreased further.

The second argument that says that cloning of human individuals is intrinsically wrong is based on the concept of the right to an open future, which Feinberg proposed and Hans Jonas called the *right of a certain kind of ignorance*.¹⁵⁾ According to these arguments, the meaning of life is based on an open future and its possibilities. This means that if we know the life-path of someone who is genetically the same as us, we know that certain possibilities are not

14) 'The Child's Right to an Open Future, Whose Child?' *Children's Rights, Parental Authority and State Power*, Feinberg, J. Aiken, W.(ed)(1980).

15) <Philosophical Essay>, *From Ancient Creed to Technological Man*, Jonas, H. Pretice-hall(1974).

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open to us so our confidence to make choices in life can be hurt. This opinion is also grounded in genetic determinism, with which we find difficult to agree. We cannot but suspect the validity of the opinion because the knowledge of the limited possibility doesn't make our life meaningless, but rather makes it possible to be more efficient in achievement.¹⁶⁾

III. Sanctity of life and human dignity

Sanctity of life and *human dignity* are two important life and medical ethics concepts, which play important roles in life and medical ethics discussions. Even though those two concepts have different histories and different content, they play a similar role in life and medical ethics discussions. In many cases, these concepts are used to close down difficult and tricky discussions because these two concepts are accepted without doubt as self-evidently sacred values.

The suddenly increased development of technology in the life and medical ethics area has become a source of discomfort and anxiety for modern people who cannot hold onto their old value system, so they produce various new options. It turns things that were taken for granted in the

16) <Cloning Human Beings>, 'Clones and Clones', Dan W. Brock. Nussbaum, M.C. (ed) Norton, New York (1998).

past into objects of doubt and discussable argument.

Such objects include not only descriptive levels but also levels of rules. Many people come to the point of doubting their own deepest and most intrinsic moral beliefs. In this situation it is natural to look for a safe foundation for tackling technological progress and moral pluralism head-on, and *sanctity of life* and *human dignity* are regarded as just such a firm and rock-solid base.¹⁷⁾

There are largely three areas with problems that cause modern people discomfort, and where at the same time, the above-mentioned two concepts play important roles. The principle that because human life is sacred and inviolable, medical personnel must restrain themselves and be particularly careful not to destroy it, is a consistent argument in discussions of life and medical ethics from long ago to the modern age. The time when the principle was introduced into the everyday political area was in 1973 when the Federal Supreme Court in America decided to legalize abortion. Since then the dignity of human life has been raised in opposition to abortion. As a second area, the principle plays an important role in debates about modern *intensive care* and the related *terminating treatment* and *ethanasia*. Anyone who questions the custom of intensive

17) 'Introduction, Sanity of Life and Human Dignity', *Sanctity of Life and Human Dignity*, Kurt Bayertz Kluwer Academic Publishers (1998), xii.

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care while emphasizing the cost of treatment and insists on the ethical propriety of euthanasia definitely comes up against the opposing view that the dignity of human life is the best value of medical treatment activities.

Thirdly, concepts like human dignity play an essential role in the ethical discussion related to technical interference in human birth and the manufacture of pregnancy. Various artificial pregnancy induction methods such as artificial insemination have become the subject of discussion as clear violations of human dignity and because of recent developments in test tube insemination and progress in genetic technology that allow various new options for human birth, the same arguments are being discussed. In the case of making things like artificial intervention in human genes, human cloning, or the creation of human-animal hybrids illegal, and therefore legalizing punitive regulations, the entire justificatory basis is the preservation of human dignity.¹⁸⁾

The reason why the two above-mentioned concepts are regarded as more important than other ethical concepts like *autonomy* or *justice* derives from the source of authority which they have on their own. But even when the fact that they have realistic authority based on their religious origins is admitted, it is still disputable whether they have reasonable and normative authority. The reason for this

18) Kurt Bayertz, *Ibid.*, pp.xii- xiii.

dispute comes from the fact that those concepts are not exactly defined, and their relative importance is not clear either.

Above all, if first we take the concept of *human dignity*, this concept has been prescribed by many scholars as an *empty formula*, which can be filled with a variety of contents. It's difficult to obtain a consistent interpretation of this concept even from legal documents. On the one hand, human dignity is dealt with as a type of human concept that has real content rooted in the western Christian tradition. On the other hand it is also related to concepts like *subjectivity* or self-determination. This kind of room for various interpretations is exactly reflected in those discussions ranging from abortion and euthanasia to genes and birth. Human dignity indeed has a meaning area so filled with differing and disputable opinions as to become a neutral platform which every different type of position can share together.¹⁹⁾

The concept of *sanctity of life* has the same story, so its mundane meaning also encompasses various difficulties. One of the difficulties is about the word itself. Does sanctity of life indicate life of every life form or only the life of humans? These two possibilities directly confront a difficulty. If life itself is sacred, it is difficult then to say

19) *Human Dignity, 'Philosophical Origin and Scientific Erosion of an Idea'*, Kurt Bayertz, *Ibid.*, pp.73- 90.

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that a human's right to live is higher than that of an animal or even a plant. But on the other hand if the sanctity is limited to human life it becomes questionable as to how to draw the morally significant dividing line between human life and non-human life. One of the most important questions among theoretical and practical problems related to this is whether all human life is in fact inviolable and is so under all possible circumstances, and therefore whether, in order to save one human life, every effort has to be expended, and at whatever cost.

From the questions above we can progress to the problem of relative importance when the demands around the sanctity of life conflict with other principles. For example, relating to the matter of distributive justice, there can be a tension between the duty to save life and the interest of an individual or a group. The resources used for intensive healthcare cannot be used for preventive medicine or education at the same time. How can priorities for distribution of resources be decided and justified? Furthermore, there can be conflict even between those two principles, sanctity of life and human dignity.

We can take two cases to show it. Sanctity of life and human dignity can conflict with each other in the frame of conflicted *interpersonal* value systems. For example let's see the case of abortion, in this case the right to live of an unborn baby and the right of a woman to decide for herself

as a basic condition of human dignity. This kind of conflict demands a class structure, which can demonstrate a priority between principles and rights. But there are various opinions about this priority, so whether life has an absolute value or can become relative compared to other values is under hot discussion.

Apart from conflicting principles between individuals, even within a single individual there can be a conflict of *intra personal* values. Cases like intensive care, termination of treatment or an extreme case like euthanasia are the most difficult ones that exemplify conflicting principles. In many cases, the family of a patient who has fallen into a comatose state with no hope of recovery (the state of brain death) can demand termination of treatment or euthanasia for the sake of human dignity. On the other hand, a doctor in charge can refuse to terminate treatment on the grounds of sanctity of life or argument from playing God.²⁰⁾

So these two concepts that can appear at a quick glance to have the same meaning can sharply confront each other in the above-mentioned cases. Even if these two concepts cannot be said to stand entirely together, they are still used for justifying morally indispensable behaviours, and at this stage of an argument, no further measures can be taken because as soon as anyone appeals to the human dignity or sanctity of life, suddenly the discussion comes to an end.

20) Kurt Bayertz, *Ibid.*, pp.xv- xvi.

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These two concepts are held to be winning formulae. Both are meant to point to the highest value, which cannot then be compared to any other thing. So while these two concepts are suggested for preventing moral relativity in theory and individual autonomy, in practice they can rather act as an obstacle for logical discussion.²¹⁾

IV. The gap between medical diagnosis and treatment

Nowadays a cherished desire for longevity and health substitutes for the cherished desire for immortality and supreme bliss that once prevailed. Recently new horizons of expectation for earthly salvation began to open up. Thanks to the development of medicine, biology and genetics we are having success in identifying human genes one after another. As this kind of technology is evolving, genetic features of health and disease are being identified more accurately and the biological structure of the human being is being investigated even down to its most basic factors. During that process, structural defects (i.e. genetic defects) or imbalances become more transparently visible. Research has moved forward under the expectation that everything will be interpreted tomorrow, if not today.²²⁾

21) Kurt Bayertz, *Ibid.*, p.xvi.

Of course it is a fact that with this kind of research new possibilities on various sides are beginning to open up. The information provided through genetic diagnosis makes it possible to protect us and our children from genetically causative factors of disease and to prevent us in advance from having ill or disabled children. However the problem is that this is only a possibility. When or indeed if it can become reality is a totally different matter.

After all, possibility suggests chance, but at the same time, it hides dangers on the other side, and recent occurrences imply a need to be on that sceptical side. But what if genetic diagnosis can lead to a much wider range of experiences? Would it then help us to live more healthily and more happily? What can the possible side effects of these health programs be? The questions keep coming, one after another.²³⁾

Gene treatment is a new method of treatment, which is designed to cure or prevent disease by delivering a new gene into a human body cell. It uses a method for replacing a defected gene with a normal gene or to put a new gene into cells so as to give a new function or to control genes that are over or under-performing. The first genetic treatment happened at the National Institute of

22) *The Social Implications of Bioengineering*, Elisabeth Beck- Gensheim, Humanities Press, New Jersey (1991), p.79.

23) Elisabeth Beck- Gernsheim, *Ibid.*, p.80.

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Health in America in 1990 with two girl patients who showed severe cases of immune-deficiency disease (ADA). They have grown up in fine health since their gene therapy and appeared on the Times, when they visited the zoo at the beginning of this year.

But gene therapy is still in its very earliest stages. At the present moment in May 2000 all together 425 clinical experiments are being progressed in the whole world, but regarding the stage of clinical researches, most of them are at the first stage, of watching the side-effects of treatment and the second stage, establishing the effects of treatment. Only 2 clinical experiments are at the third stage of comparing the effects of different treatments, principally because research into the gene *vector* which delivers the genetic material during gene therapy hasn't yet reached a mature state. The sudden death of a 17-year-old boy, Jessie Jelsinger, who had been treated for the OTC-deficiency disease in Pennsylvania University Medical Centre in America was a shocking accident, which threw a certain amount of cold water on the prospect of successful gene therapy.²⁴⁾

When we are exposed to the idea that we ourselves or our spouse or our children might have a genetic disease, we confront the difficulties of relationships between spouses

24) 체외 또는 체내유전자 치료법 , '유전자 치료' 윤리 안정성 토론회, <한겨레신문>(2000.10.2).

or parents and children. In this case genetic diagnosis can actually supply the objective ground for decision-making but in most cases doctors cannot give much treatment other than diagnosis. This can be called the *dilemma of genetic diagnosis*. This is the difficulty caused by the fact that the possibility of diagnosis is going forward much faster than that of treatment. If the result of diagnosis is good, it is relaxing but if it is bad, it just gives a heavier burden and more conflicts of conscience. People are just left in fear and despair without any possible solutions, as the diagnosis of danger increase with each developing technology, and we can all end up as latent carriers of genetic danger.²⁵⁾

Imagine that you have to live with the knowledge that you will contract a serious disease within a few years and there is no proper treatment for it. Imagine that you are the parents of a newborn baby who has a causative factor for a serious disease. Will you let him or her know about this or keep it to yourself? Even though it is not certain that such a disease will occur one day, simply to live with knowledge of the probability makes leading a normal life quite difficult to guarantee and one can lead a rather unhappy life overshadowed by dark potential. Even just the knowledge of a simple statistical fact can draw a black cloud over someone's whole life.

On the other side knowing genetic data can be welcomed

25) Elisabeth Beck-Gernsheim, *Ibid.*, p.87.

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when it allows people to confront a challenge with more responsibility compared with a state of ignorance. In spite of this, you still can't actually ignore the potentially negative side effects. So now we're looking for a new path through which we can make a whole new different approach with a different view to the problem. Are those assumptions, which are immanent in genetic treatment right? Can you say that knowing something is always better than not knowing? You can say that it is not always better. How about the loneliness of confronting the truth and the burden which is immanent in knowing? Are scientists forgetting the bliss of freedom, the freedom of not knowing? Don't we have to insist on the *right not to know*, on the right to ignorance as well as the right to knowledge?²⁶⁾

26) <*The Right to know and the Right not to Know*>(Avebury Series in Philosophy), Ruth Cadwick(ed), 1997.