

**CONFERENCE OF EUROPEAN CHURCHES  
COMMISSION FOR CHURCH AND SOCIETY  
WORKING GROUP ON BIOETHICS**

**GENETIC TESTING AND  
PREDICTIVE MEDICINE**

**Summary**

Over the last few decades, we have seen a major change in the field of medicine, due to the development of the science of human genetics. The traditional focus on *diseases* themselves has now turned towards the *risk of illness*. This evolution may make possible the understanding, treatment or even prevention of some diseases. With the help of good quality genetic counselling families, may in some cases, have the opportunity to avoid passing on to their descendents serious conditions and thus change the destiny which weighs over those affected.

However, these undeniable advances must not be considered as entering a new promised land, where all health problems will be solved. Far from it! First, most actual predictions:

- are less certain than may be claimed,
- do not yet lead to therapeutic solutions either through conventional treatment or the much heralded gene therapy, which is still a long way from becoming reality.

While we may be encouraged by many developments in medical genetics, it is advisable not to nurture false hopes. We also need to help individuals to come to terms with the reality of their genetic make-up (including any genetic mutation) even though this may not be defined absolutely. Every human being is special. Their identity consists of much more than their genes. In addition, predictive medicine brings with it real difficulties which must be faced squarely:

1. At the level of the individual, the main difficulty lies in the reversal of the perception of time. Normally, we perceive the future as something open and not determined, as it were with a thousand and one prospects. This open and indeterminate character provides the framework for hope and possibilities for action. Genetic prediction, in so far as it is presented as accurate and is believed to be so, would now turn this order upside down. What does it matter what action we decide on, if some sort of predestination has decreed everything in advance, and we can do nothing to change it? Not only does it describe the future as if this was something determined absolutely, “written in our genes”, but also this sense of an inescapable fate gradually takes over the present. Our present life would be lived as nothing more than a preparation for and anticipation of its end. The final outcome, like a metaphorical cancer, invades every space and everything revolves around it.

The God of the Bible liberates the future. At the moment of the exodus from Egypt as well as on Easter Morning, He breaks the chains of destiny and opens the way to freedom beyond slavery and death. This is why, when the gospel message is applied to the case of predictive medicine, we have to take into account the essential fact that in Christ, and with the God of the gospels, no destiny can keep people prisoner. The doctor-patient relationship, and all forms of appropriate genetic counselling must then respect the autonomy and freedom of individuals by helping them make their own responsible decisions, in the light of their particular circumstances.

2. The development of predictive medicine may indeed have positive results for public health and prevention in quite a number of cases, but its importance should not be exaggerated. It should not be presented as the key to future medicine. The risk here would arise from placing a naive reliance on the absolute power of science and genetics, or illusory expectations about the benefits they can bring. Such reliance could turn into a new kind of idol worship and could also lead to “slippery slopes” which challenge important aspects of human freedom and hold back the building of truly responsible attitudes. Moreover, even if predictive medicine does not, as some maintain, open the way towards eugenics, it has contributed to the current trend towards the search for the “perfect child”, which we would denounce. The risk of discrimination and segregation is very real and must be carefully guarded against.

## **I. A NEW BRANCH OF THE ART OF MEDICINE?**

In general terms, medicine deals with the treatment of changes to our normal state of health which adversely affect the length and/or quality of life. The effectiveness of medical intervention is traditionally assessed in terms of the survival of the individual on the one hand, and on the other, the quality of life thereafter. For the last few decades one has noticed an important change in this perception, following developments in the science of human genetics. The traditional focus of doctors’ attention on an *illness* which is already apparent has now shifted towards the *risk of illness*.

### **The beginnings of predictive medicine**

The study of the many diseases associated with specific alleles of certain genes has since 1972 inspired the idea of a form of medicine based on the genetic testing of individuals who may be at risk of developing a given illness. This is what is known as predictive medicine. The concept has evolved since then and today, thanks to advances in molecular genetics and our increasing knowledge of the human genome, the use of predictive genetic testing in medicine is becoming increasingly common<sup>1</sup>. The aim of predictive medicine is to identify in healthy subjects mutations associated with a particular disease. Genetic analysis allows the identification of genes which might lead to the development of a particular disease. This is known as presymptomatic diagnosis.

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<sup>1</sup> In Italy the use of genetic testing is increasing by 30% a year (Dallapiccola et al, 2000)

Medical practice is increasingly oriented towards the prevention of disease, that is, on identification and treatment even before the appearance of symptoms. The criterion for effective treatment based on the concept of “quality of life in survival” changes to one of the “probability of survival”. While in the past curative medicine developed towards preventive medicine, and then to predictive medicine, “the order has now been reversed so that prediction precedes prevention which in turn precedes treatment”<sup>2</sup>.

There is a synergy between this evolution in medicine<sup>3</sup>, and the development of knowledge about the human genome, the economic involvement of the biotechnology industry, and the spread of patents for DNA sequences<sup>4</sup>. This synergy has encouraged the development of a remarkable number of genetic tests, for which there is a continually expanding market.

Predicting the appearance of certain illnesses before symptoms appear has obvious advantages in prevention and early treatment, but questions need to be asked about the limitations of prediction, particularly where no therapeutic or preventive measures exist as yet<sup>5</sup>. It is also important to take into account the possible secondary effects of diagnosis, both on the life of the individuals concerned and on the wider society, and what is at stake economically as these tests are developed<sup>6</sup>.

### **The conditions revealed**

Illnesses which may be detected by genetic analysis fall into four categories according to the type of DNA and mutation concerned:

- **single gene** defect diseases, which are very varied<sup>7</sup> but are rare, are caused by a mutation on a single gene associated with a high risk of developing the illness
- **multifactorial** diseases (heart disease, asthma, diabetes, hypertension, etc) which are much more frequent, and are due to the interaction of several genes combined with environmental factors. These are transmitted by natural mechanisms which follow the laws of probability, and are subject to great variability and complexity
- **chromosomal** abnormalities which are one of the main causes of prenatal mortality and congenital malformations; they are caused by anomalies in the number or structure of chromosomes
- **mitochondrial** abnormalities due to mutations in mitochondrial DNA.

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<sup>2</sup> J. Dausset, *10 Nobel per il futuro*, IV edizione, Milano, 1996.

<sup>3</sup> An evolution which was supposed to modify radically the prognosis of many diseases, but which is now seen, in the light of epidemiological data, to be partly an illusion. Currently, interventions aimed at early diagnosis are limited to those cases where there is a demonstrable effectiveness in terms of survival and/or quality of life.

<sup>4</sup> 3 million applications for patents on human DNA sequences have been lodged in the USA, while there are only one-hundredth that number of human genes.

<sup>5</sup> Which is unfortunately the case for most genetic diseases.

<sup>6</sup> a) Comitato Nazionale per la Biosicurezza e le Biotechnologie “Linee guida per test genetici”. Presidenza del Consiglio dei Ministri, Roma, 1999

b) CCNE “Génétique et médecine: de la prevision à la prévention”, Avis n°. 46, 30 October 1995

<sup>7</sup> To date, more than 6500 are known, including Huntington’s disease, cystic fibrosis, polycystic kidney disease, etc.

## **The finalities of predictive medicine**

It is obvious that the rise of predictive medicine may bring about a profound transformation in medical practice and even social cohesion as a whole. As Jean Dausset writes: “In contrast to clinical screening which identifies in a population those individuals who are already ill, genetic screening is probabilistic because it identifies those at risk while they are healthy”. Similarly, “In contrast to preventive medicine which is mass medicine (vaccination of whole populations being a typical example), predictive medicine is personalised and limited to those individuals who are vulnerable”<sup>8</sup>. If we consider only the questions raised by testing on adults<sup>9</sup>, two types of outcome may be identified:

- An outcome for the individual which aims to give the person concerned information about his/her condition. This information may be directed either to implementing various forms of prevention (where they exist), or simply to knowing the information, and so being warned.
- A collective outcome which affects public health, either by contributing to fundamental research, or by aiming to eradicate serious and disabling genetic diseases in a given population.

## **II. THE INDIVIDUAL FACED WITH CHANGES IN MEDICINE RESULTING FROM THE USE OF GENETIC TESTING**

In the field of genetics, where our knowledge is constantly and rapidly evolving, medical applications follow one another changing continuously, thanks to spectacular technical progress. This makes it difficult to foresee the future development of genetic diagnosis and its role in medicine in years to come.

In cases where prevention or early treatment are possible, the benefits of predictive genetics are undeniable. On the other hand, the possibility of advanced knowledge of having a susceptibility to a pathology for which there is neither prevention nor effective treatment raises major ethical questions. It poses the problem of the medical, psychological and social risks for individuals who consent to undergo tests. The use of these tests does in effect raise real ethical issues.

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<sup>8</sup> Cf. note 2.

<sup>9</sup> There are also tests carried out on embryos or fetuses which aim to assess the quality of the genetic inheritance of the unborn child (prenatal diagnosis, or pre-implantation diagnosis in the case of IVF).

Here we will examine mostly the general case of testing for adults, while the more specific questions raised by prenatal testing and pre-implantation diagnosis will be considered by the Working Party in a later document.

Genetic testing on adults (in particular presymptomatic and on genetic susceptibility) have particular characteristics which make them quite different from any other biomedical analysis carried out for diagnostic reasons. Let us look at these characteristics.

### **What does testing aim to achieve?**

Genetic diseases are caused by changes (mutations) in an individual's genetic inheritance. Mutations which occur in the genes in germ cells (ova and spermatozoa) will be present in all cells of the organism descended from the cell in question. The organism will have the disease and transmit it to all its descendants. Today, it is possible to detect mutations using a variety of cytogenetic and molecular genetic techniques (genetic tests)

The various techniques used for gene tests are all roughly similar. It is though important to define some distinctions according to the function and purpose for which they are used:

- a) to obtain or confirm a diagnosis in persons with genetic diseases (*diagnostic testing*);
- b) to establish whether an asymptomatic (ie healthy) person carries a mutation responsible for a disease which will appear later in life, perhaps only in old age (*presymptomatic testing*);
- c) to identify carriers of mutations which constitute a potential risk factor on interaction with other genes and the environment (*predictive testing for genetic predisposition*);
- d) to identify people who are clinically healthy but are heterozygous carriers of genetic diseases which occur particularly frequently in a given population (*testing to detect heterozygotes*);
- e) to be able to identify a particular person by the analysis of regions of DNA polymorphism which are specific to each individual (*DNA fingerprint*).

These genetic analyses can be used either on individuals or members of certain families, on the basis of particular medical indications (*genetic testing*), or on whole populations in the absence of any particular indication (*genetic screening*).

### **Specific features of analysis by genetic testing**

Whatever its diagnostic outcome, genetic testing has particular features which are not without consequence for the person concerned and for the doctor/patient relationship.

## 1. Genetic testing is based on *probability analysis*

Genetic analysis on subjects at risk leads to the identification of the gene governing the hereditary predisposition and is limited to a quantification of the degree of risk the individual is exposed to.

But probability is difficult to quantify, particularly in the case of single-gene diseases, where the mutation is expressed at different levels in different subjects (variable penetrance), or of polygenic diseases.

The causal mechanistic link between the symptoms of a declared illness and its diagnosis (the object of therapeutic medicine) becomes blurred when evaluating the possibility that a healthy subject will contract a given illness in the future (the object of predictive medicine), which is very difficult to make precisely.

2. **Genetic testing modifies the *relationship between doctor and patient*.** This new type of relationship is characterised by the following features:

- The aim of "beneficence" – i.e. treating the patient – ceases to be the main outcome of medical intervention<sup>10</sup>. Although of course therapy remains in the background, the main emphasis is on looking further into the detail of the diagnosis, rather than just managing the illness or curing it. This new perspective has important ethical implications and respect for autonomy becomes more important than the principle of beneficence.
- Genetic analyses provide information on genetic inheritance, which is one of the basic elements of biological identity and characterises the individual's uniqueness. But at the same time, this particular identity is shared with other people (members of the immediate family and descendants). *This introduces into the doctor-patient relationship other individual and collective subjects.* While they are third parties relative to the primary relationship between the doctor and the patient, they share genetic traits with the patient. This situation often gives rise to conflicts of interest, which must be faced with respect for the various family members' right to know or not know<sup>11</sup>.
- Subjects who undergo predictive testing are not demonstrating any symptoms and *therefore have different expectations from those of persons who are already living with the reality of illness.*

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<sup>10</sup> This is seen clearly when we consider the following alternatives proposed to women who have been proved to be carriers of a genetic mutation associated with breast cancer:

- a) strict mammographic observation (which implies repeated exposure to X-rays)
- b) preventive treatment with hormonal chemotherapy (purely experimental)
- c) prophylactic mastectomy (a mutilation whose deep symbolic repercussions need no emphasis).

<sup>11</sup> With the aim of safeguarding this right, the Council of Europe proposed to confer an intermediate status on members belonging to the genetic lineage of the subject who had undergone testing, which would distinguish them from third parties in the strict sense of the word, in order to give them a hybrid legal protection (Recommendation R 97/5)

It may even be said that predictive testing is not a means put at our disposal by science, but rather a possibility which is withdrawn from us<sup>12</sup>. By removing from death the quality of *indeterminate certainty*, predictive tests have turned the sense of temporality upside down; existence is no longer the realisation of a project but rather the execution of a (genetic) programme.

The results of predictive genetic testing have a practical and essential symbolic impact, particularly in the case of the numerous serious diseases for which there is no effective treatment or prevention. They may signify, on the one hand, a condemnation or, on the other hand, be extraordinarily liberating. What is the value of the classic criteria of benefit and harmful effects when prescribing an examination for a patient genetically predisposed to an incurable disease? Will this examination not set him apart, so that even though he is not yet ill and may never develop pathological symptoms, he will be identified as different from all those who do not carry genetic abnormalities, and this information may, at one stroke, radically transform the rest of his life?

## Ethical consequences

The particular features mentioned obviously have important implications for ethics. Problems now presented are :

- *Respect for the principle of autonomy should be taken into consideration even more than usual.* The development of predictive medicine must be accompanied by a new ethic principle which “bases the medical relationship on respect for the patient’s freedom to decide”<sup>13</sup>. This stipulates that it is essential that the choice of individuals who are offered a test should be entirely free, autonomous and founded on truly informed consent in the light of the “innate and non-accidental” nature of genetic information revealed by tests, whose “interpretation with regard to one’s representation of oneself, and also the consequences for one’s present and future life are of major importance”<sup>14</sup>
- To ensure that genetic testing is done in the interest and for the well-being of the person concerned and with their free and informed consent, it is vital to ensure that before undertaking the test, **genetic counselling** appropriate to the tests and their implications is available.<sup>15</sup>

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<sup>12</sup> This point is brought out in remarkable fashion by J. Porée, in “Prédire la mort. L’exemple de la maladie de Huntington” (“Predicting death. The model of Huntington’s disease”), *Esprit*, June 1998, p.17-26

<sup>13</sup> G. Terrenoire, “Familles et médecins face à une maladie héréditaire : l’interrogation éthique partagée”

(“Families and doctors faced with hereditary disease: the ethical question divided/shared”, Laennec, March 1999

<sup>14</sup> CCNE, “Génétique et médecine: de la prévision à la prévention”, Avis n° 46, 30 October 1995

<sup>15</sup> Article 12 of the Convention on Human Rights and Biomedicine of the Council of Europe: “Predictive testing for genetic disease shall only be undertaken for medical or medical research purposes, and only with appropriate genetic counselling”.

The aim of genetic counselling offered by the team of professionals is to *inform* the persons who are faced with the choice of whether or not to undergo a test, *to offer them support* before, during and after the test, and to *communicate the results* in terms which enable lay people to understand them and *to encourage free and independent decisions*<sup>16</sup>.

In this context, the European Group on the Ethics of Science and New Technologies, in a declaration in February 2003 denounced the dangers of advertising and open selling of genetic tests via the Internet. It affirmed that the uncontrolled distribution in the absence of appropriate genetic counselling risks trivalising the tests and turning them into consumer goods, giving way to a demand which is increasing and unjustifiable. Given the particular nature of genetic information, this situation could unleash social and personal conflicts and lead to the violation of fundamental rights such as the right to equity.

It must be noted however that predictive medicine is too recent a phenomenon to allow one to evaluate whether the conditions in which testing for predisposition is offered and carried out can really guarantee a process of decision making which is really founded on the cultural values, needs and moral convictions of each person who has to decide.

Genetic counselling is far from an easy task, so it is important that those who offer it are appropriately trained. It is obvious that there is also a pastoral challenge here and it is advisable that pastors and chaplains should be trained to deal with these difficult problems.

- It is a part of the human condition that we live in the face of an open future which offers us various possibilities and potentials. This open future confers freedom and allows action and commitment. This applies on an objective level. If our destiny seemed inescapable, we would not take action and the very word responsibility would have no meaning. It also applies on a subjective or psychological level, since the impression that a predetermined future is weighing down on us necessarily influences the way we perceive and build our own lives. It is true that this knowledge may be positive, in cases where medicine makes prevention possible, or where it is possible to adopt a style of life suitable to prolong life for certain conditions, and also on a moral and spiritual level when it allows preparation for what must inevitably happen<sup>17</sup>. But it must always come down to a matter of choice. Every individual has a right to know, not to know or refuse to know. There is no instance in which individuals may have forced on them information which they do not wish to have. Since, as we have seen,

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<sup>16</sup> A “good” counsellor should be non-directive, sympathetic, available for dialogue, and should have experience of the different aspects of verbal communication while also knowing how to establish a dynamic relationship other than by words, and should also know how to manage constructively ethical conflicts. It is with these requirements in mind that guidelines on genetic counselling including information (to help understanding of the transmission mechanisms involved in genetic features) and multidisciplinary clinical practice (for management of the psychological and relational aspects of risk prediction) are currently being evaluated.

<sup>17</sup> The question of choice as regards procreation (which will be considered by the group in a later document) is more difficult: it implies third parties, who are the spouse (of course) and the unborn child, and also society in general, which will be affected by the consequences of a given decision. Arriving at a responsible decision must take all these parameters into account.

genetic data are by their very nature shared by several members of the same family, it is vital to ensure that the will of some who seek to know does not go against the will of those who do not want to know. It is important to take much more account of this aspect before embarking on unlimited genetic research. In all cases, medical confidentiality with respect to third parties must be strictly observed

- It is particularly important to emphasise the open nature of the future as mentioned above. What happens when one resorts to genetic testing? What do people hope to do? For Christians, the future, as opened to us by God Himself, cannot be closed off by any power other than Himself. We must always therefore remember that the tests are for the most parts probabilities and that in any case, even though the chances of escaping a genetically prescribed fate may seem infinitesimal, the future cannot be predicted absolutely. In fact, the only thing that we can be sure about is that we will all die some day; but the time and circumstances of our death will always remain indeterminate. Now death has been conquered by God through Jesus Christ, so that faith in Christ crucified and risen, dead and alive is a sort of “anti-destiny”. This belief is not false opiate, but rooted in God, it is an unceasing revealing of strength and courage to be, of the capacity to overcome even the power of death. Moreover, it is not possible to ignore the fact that a person’s moral and spiritual health are decisive components of bodily health, and of the manner in which they cope or not with their situation and fight the disease which afflicts them<sup>18</sup>. From a merely pragmatic point of view, then, it is important to weigh up the advantages and disadvantages of access to a knowledge which in any case can only be incomplete.

### **III. PREDICTIVE MEDICINE AND COLLECTIVE ISSUES**

The use of predictive medicine also has profound repercussions for collective issues. We note particularly the following elements :

#### **1. Public health and prevention**

The possibilities opened up by predictive medicine lead to policies of prevention. Being able to predict what might happen one day in the future allows preparation of strategies for fighting conditions before they show themselves, or for delaying their appearance or even avoiding them<sup>19</sup>.

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<sup>18</sup> The make up of a life is much wider than just its simple biological and/or medical characteristics, but even in this area, the placebo effect is testimony to the extraordinary effect of the psychological component on physical aspects.

<sup>19</sup> On this subject, a 1995 report of the French CCNE mentions the possibility of “the prevention of congenital handicaps, of illnesses of adolescence and adulthood (diabetes, cancers, cardiovascular disease), and of old age (Alzheimer’s disease). It is worth noting however that the preventive function of medicine has always been with us; it is just now, with the development of predictive medicine, that it has taken on a particular hue.

These prospects cannot be purely and simply ignored. The near eradication of thalassaemia in Sardinia<sup>20</sup> provides us with an example of success, but also an illustration of the dilemmas. In the same way, one cannot either reject out of hand the decision of the Icelandic parliament<sup>21</sup> to allow their population to serve as a genetic research “laboratory”<sup>22</sup>. The fact that these measures are linked with private funding however, leads us to wonder if these populations are not in fact being treated as mere objects.

It is true that the use of genetic data on the Icelandic population raises the major ethical question of double protection of medical confidentiality and respect for the privacy of the individual which should be applied to these data. The Icelandic parliament’s decision has given a new impetus to the debate which sets the right to respect for private life against the fact that this right should not harm the general interest (equally important) of sick persons who could benefit from the results of the genetic research.

In an attempt to find a balance between these two positions and to establish a common ethical reference framework at the international level, the United Kingdom Human Genetics Committee put forward the concept of *genetic solidarity and altruism* : the sharing of genetic information must be accompanied by respect for the person, which implies observing the principles of respect for the privacy of the individual and the confidentiality of personal genetic information, as well as the principle of free consent and non-discrimination<sup>23</sup>.

The increasing amount of research being carried out by private bodies on targeted populations make it even more important to address this question urgently, especially where this relates to developing countries. Targeting these populations, or even groups of individuals in our countries, may turn into marginalising and stigmatising them, and so prove discriminatory.

As regards prevention, it is well known that public health campaigns (against alcohol and tobacco for instance) have difficulty in bearing fruit. While prevention in the form of vaccination, for example, has been remarkably successful, it is difficult to see how such actions related to genetic data can lead to similar results, except to encourage unacceptable forms of eugenics. Finally, the prospect of collective care arising from predictive medicine rests on the illusion derived from the idea that “everything is genetic”, by-passing cultural, social and individual elements in the life of every person on the quality of health they may or may not enjoy.

In conclusion, while it cannot be denied that there may be positive results of predictive medicine for the area of prevention, its importance should not be overestimated. There is in effect a risk that, far from encouraging responsibility, genetics may become a sort of *deus ex*

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<sup>20</sup> In various parts of Italy (not only Sardinia but also Apulia and Ferrara province), thalassaemia has been brought under control with a 90% decrease in incidence in just a few years, by the setting up of a public genetic counselling and prenatal diagnosis service, alongside an efficient information campaign.

<sup>21</sup> In 1998 the Icelandic parliament passed a law allowing the collection and processing of medical, genetic and genealogic data from the whole population by an American-financed private firm, deCode Genetics, which was also awarded exclusive rights to the commercial use of the data bank thus created for 12 years. Following on from this, the pharmaceutical company Hoffmann-La Roche will be able to use the Icelandic database for research on the genetic origins of 12 common illnesses.

<sup>22</sup> The use of genetic databanks may supply useful information for the understanding of the aetiological mechanisms of some diseases.

<sup>23</sup> Human Genetics Commission, *Inside Information: Balancing interests in the use of personal genetic data*, 2002

*machina* which is reckoned to be the miraculous solution to all problems. The means of achieving results in this field and the consequences for public health, must be the subject of wide debate and rigorously democratic decision-making with scrupulous respect for the fundamental rights of the human person.

## **2. The threat of liberal eugenics**

Faced with the use being made of some advances in genetics, voices are being raised calling attention to what they call “liberal eugenics”<sup>24</sup>. It is important to distinguish this from the massive eugenic programmes decreed from on high by those in power, which have been justly condemned as a crime against humanity. What is being referred to here are decisions made by individuals who want the “best children possible”. But it has also to be recognised that these decisions are made in the context of a social pressure. It is clear that the many advances in medically assisted procreation and genetics are coinciding in one way or another to create possibilities for choices which take on a sense of a certain form of selection. Advances in predictive medicine have reinforced this tendency, giving rise to many fears. It is by no means certain that the term “eugenics” is really the correct one here<sup>25</sup>. Eugenics is in effect the fruit of a deliberate programme to improve a race or species. Now this is not the case for the individuals we have been considering, where the intention is to escape misfortune. It is true that the concept of “misfortune” is subject to many varying interpretations and it would be reasonable to think that our overprotected western societies tend to defend their comfort to the detriment of real solidarity. But this is far from certain and there is still a need for precise analysis, discussion and debate<sup>26</sup>. Also, *imposing* on parents a choice which is not their own and that they then cannot deal with, amounts (or would amount) to society or the State adopting an attitude parallel to that of “traditional” eugenics which seek to control procreation and family life. While it is true that society has a duty to make a place for those whom life has injured or disabled, and to accord them a place, it is legitimate to think that society should not attempt to provide a substitute for the wishes and the inner strength of parents. Society itself can benefit from giving responsible support to families who choose to welcome children who will have special needs. In any event, the Churches should continue to nurture this debate and promote it with a view to strengthening truly responsible societies and solidarity.

## **3. Healthcare systems, equality among citizens and solidarity**

In those countries where there are several forms of provision of health care (medical insurance, social security, etc), these systems are all based on what John Rawls called a “veil of ignorance”. The sharing of risks over populations implies that it is not known – and there

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<sup>24</sup> Cf. for example J. Habermas, *The future of human nature. Are we moving towards liberal eugenics?*, 2002

<sup>25</sup> In France for example, in recent years births of trisomic children have reduced by half. On the other hand, advances in medically assisted procreation and neonatal care (delivery at 25-26 weeks of children weighing just a few hundred grams) have increased risks on birth. Overall, the number of birth-related handicaps is in fact on the increase.

<sup>26</sup> The Working Group of EECCS (predecessor of the working group of the Church and Society Commission of KEK) had already given its opinion on the embryo problem in *Medically Assisted Procreation and Protection of Human Embryos*, December 1996

is no search to know – which people are more susceptible than others to damage to their health. In these systems, all human beings are, in principle, equal with regard to risk. In this sense, our collective ignorance is fundamental to our solidarity. The development of predictive medicine therefore represents a grave threat to these systems, by allowing us to see in advance those who are more at risk than others.

This is particularly true of certain areas:

- In genetic research itself, where confidentiality, and the rights of the weak and the small, equality and equity must be given absolute protection by national and international communities.
- In employment law: no-one should be penalised for their genetic characteristics. While it is true that some of the latter can be a counter-indication for certain types of work, it is for the person concerned to come to his or her own decision on the consequences of a diagnosis (which must be protected by medical confidentiality).
- In social protection and insurance: no one should be excluded from the solidarity pact which constitutes the insurance system, on account of their genetic characteristics. Since UNESCO has even declared that the human genome is “the common heritage of humanity”, all human *beings have an inalienable right to share in this heritage.*

## **Conclusion**

The God of Jesus-Christ shows no partiality (Deuteronomy 10.17, Acts 10.34, Romans 2.11, Galatians 2.6). The Creator of all human beings, He laid down their equality as images of God. He is the God *par excellence* of non-discrimination. When we apply this assertion to the problem of predictive medicine, it means that no person or group of persons can be subjected to segregation or discrimination because of their genetic characteristics. This central affirmation has repercussions both on the conduct of genetic research itself, and on labour law, social protection and insurance programmes.

The second crucial point is that the God of the Bible liberates the future. Through Jesus Christ, God overcomes “fate” in all its forms, including genetic determinism. God opens the way to freedom.

Finally it is very important to respect the autonomy and freedom of individuals by helping them to make their own decisions.

There is a need to initiate free and true debate in all of these cases, and to formulate truly democratic decisions.

October 2003

