

The Human Genome Project: Hopes and Fears

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What Is The Human Genome Project?

The Human Genome Project (HGP) is the most audacious and far-reaching scientific project ever undertaken. It promises to provide the skeleton key with which we shall unlock all genetic diseases and all genetic components of our natures. It promises to put into our minds knowledge un-imagined even a few years ago and into our hands powers similarly undreamt of. US Vice-President Al Gore has suggested that the implications of HGP will make the atomic bomb seem trivial. In an address to the Pontifical Academy of Sciences just over a year ago, Pope John Paul II turned his mind specifically to the question of the Human Genome Project (HGP). He said that "projects for human genome analysis are rich in promise but also imply innumerable risks."

Genome Mapping

The genome is the sum of all the DNA contained in the paired set of 23 chromosomes which we inherit from our parents, which are in turn found in almost every cell of our body. It is the sum total of our genes, of which there are 50-100,000. Chromosomes are very large DNA molecules, containing 3,000 genes on average. Between the genes are long stretches of DNA which serve as 'fillers'. DNA is composed of four different types of molecular units, called bases, named A, C, G or T and strung together in a long sequence. In human beings the genome contains approximately three-billion pairs of DNA.

The first phase of HGP involves mapping all the genes in the genome of the typical human cell. This is no small feat: if all three-

billion letters contained in one cell were written down, they would fill roughly two hundred 1,000 page telephone books. The ultimate aim of HGP is to determine the entire sequence of DNA base pairs in the human genome and the links to characteristics of the person. This project is expected to cost many billions of pesos and will alter the very structure and direction of the world's scientific community. It is an exciting project and one which should inspire awe in the face of the marvels of modern research science, awe at the complexity and beauty of life in its origins and development, awe in response to creation and thus to the Creator.

As Pope John Paul II (1993) has said, "one cannot but encourage these studies dedicated to deciphering the human genome and to analysing the results to gain greater knowledge of molecular biology and the genetic causes of diseases... The constant improvement of our knowledge of the living being is in itself good, because the search for the truth is inherent in the human being's primordial vocation and is the first praise addressed to the Creator."

Until recently gene hunting has been like looking for a needle in a haystack. But with a high resolution map of the genome to guide the search, scientists will be able to find mutations in a particular sequence and thus the genetic factors associated with particular conditions, good or bad. We should not exaggerate the possibilities here. Turning sequence information into causal knowledge is very problematical, principally because of polymorphism; turning causal knowledge into therapy is even more difficult. Hardly a week passes without a media announcement of the identification of a possible genetic cause of some human characteristic or condition which, with more investigation (and research money, of course), may lead eventually to improvements or cures.

In the last year or so genes have been identified which are thought to confer various degrees of predisposition to heart attack, lung cancer, breast cancer, uterine cancer, ovarian cancer, colon cancer, osteoporosis, and even male homosexuality. *Intelligence, criminal and domestic violence, schizophrenia, alcoholism, drug addiction, depression, sexuality, and various other personality features and behavioural dispositions, as well as most physical features such as height, body shape, colour, athletic potential, beauty, allergies, asthma, diabetes, longevity, have all been said to have genetic determinants also.* David Roshland, the editor of the prestigious American journal, *Science*, even

attributes homelessness and unemployment to genetic defects! HGP promises to tell us more and more...

The potential applications of this knowledge are also exciting. As the Pope has observed, the HGP promises "new horizons in genetic treatment and therapy with respect for the life and integrity of...patients, born and unborn, who are affected by what prove most frequently to be lethal [or at least severely debilitating] pathologies."

IVF and Non-Therapeutic Human Embryo Experimentation

But we must not allow ourselves to be blinded by our excitement either with the science or with its technological applications. We should consider, for instance, the means by which we come across this information.

In another place* I reviewed the ethical and social implications of a range of reproductive technologies, taking as my central case simple IVF. I argued that even such relatively uncomplicated procedures commoditize the unborn child, treating him or her as a laboratory manufacturing product and procreation or family-making as a manufacturing process. I suggested that we thereby engage in a process which demeans human life and the process of transmission of that life. I also argued that this has been part and parcel of a great deal of death-dealing laboratory activity in which very early human lives have been the victims.

Non-therapeutic and destructive experimentation upon human embryos is a homicidal activity and forbidden by the precept against killing the innocent and the first precept of medical ethics: *primum non nocere*. It also reduces the embryo to the status of a laboratory animal, a commodity, manufactured and disposed of to satisfy the interests and desires of others, and is thus contrary to the Golden Rule and the precept never to treat a person merely as a means to other people's ends, but always as an end in him or herself.

Fortunately gene mapping and its associated experiments and technologies do not, of themselves, require non-therapeutic human

* See "The Brave New World of Reproductive Technologies" in *Philippiniana Sacra*, 89 (1995) 277-291.

embryo experimentation. Here the Vatican Instruction of 1986, *Donum vitae*, has proved a prophetic and very useful guide. So as long as we keep foremost in our minds the need to respect human life in its transmission, origins and development, right through from conception until death, HGP can remain a gift rather than a threat to humanity.

Screening For Genetic Defect

As I have noted, a great many sicknesses are genetic in origin, or at least have a genetic component, and HGP will allow us to identify more and more of these. As a result we will be able to forecast that certain people are likely to suffer certain effects in later life, to propose various régimes to minimize such risks or effects, to avoid certain high-risk work situations, diets, environments or activities, and to identify the carriers of diseases who may pass them on to their children and give them appropriate genetic counselling.

Increasingly employers and insurers want their prospective employees or policyholders genetically screened so that they can avoid taking on any high risk people. The implications for privacy, autonomy, employability and health are obviously enormous. In addition in many countries today people are tested before marriage, or before begging a family, or after falling pregnant, to see whether they carry a genetic defect. More often the babies are tested while in the womb, or in the case of IVF babies, even while still in the test-tube. HGP is vastly increasing the range of defects we can screen for. But why do we do so? One good reason is so that carriers can make responsible decisions about their sexual and procreative activities.

But even if all those with particular genetic diseases are prevented from reproducing, this will not eliminate the heterozygous carriers who will continue to transmit defects dependent on recessive genes; to eliminate these defects, even if identification were technologically possible, would require a large number of people to be forbidden or discouraged from marrying and/or reproducing. Moreover, as defective genes are eliminated from the gene pool, they are constantly being replaced by mutations caused by environmental or random factors. Nonetheless, for particular couples, perhaps with a long history of disorders in their respective family trees or of miscarriages in their own attempt to grow one, this kind of information may have its legitimate uses.

Another good reason for genetic screening is to give parents and doctors the information. This has some immediate advantages such as reassurance for those mothers who are found not to be carrying a handicapped child, and time to treat those genetic disorders which are treatable during pregnancy. Sometimes a simple drug, hormone or vitamin supplement administered to the mother will vastly improve her child's chances if the defect is identified early enough. Sometimes direct therapeutic interventions upon the child while still in the womb will be possible. And whether or not such corrective interventions are possible, there may be benefit in preparing parents and others before the birth for the difficulties ahead. There are of course costs and risks, such as risk of foetal loss or injury, maternal hazards and anxieties, and false reassurance.

Of course the most common use for this information is to give the parents the option of aborting a handicapped child. Many gynecologists and genetic counsellors report that in every case they have dealt with of screening for a particular defect abortion has followed a positive result. Sometimes these tests are of course inaccurate, so that some healthy babies are lost in the effort to ensure that unhealthy ones do not come to birth. But for the great majority of those who are found to have genetic disorders following screening death before birth is the result.

Somatic Cell Gene Therapy

What kinds of gifts does HGP promise? The first, and least controversial one, are techniques for fixing people's genetic diseases. Somatic cell gene therapy is aimed at treating or preventing a disease in the somatic or body cells of an individual patient who has that disease. It is commonly distinguished from germ-line gene therapy which seeks to correct a genetic defect in the reproductive cells of a patient so that offspring of the patient would also benefit from the correction. Somatic cell gene therapy will occur in various ways. Adenoviruses may be developed which will invade the lungs of cystic fibrosis sufferers and introduce a corrective gene into their lung cells. Gene-splicing will allow scientists to rearrange, remove and add genetic material to defective cells. Cloning of cells of which there is a shortage will be possible: thus a patient might be given a bone marrow transplant of cloned copies of their own healthy bone marrow cells. A whole range of products such as human growth hormones, insulin and so on will be produced using such techniques.

Somatic cell gene therapy is, in important respects, analogous to other experimental forms of transplantation, and it should be assessed in the same way: by considering the benefits, burdens and risks of both treatment and non-treatment; by considering whether its use is consonant with the profession and vocation of medicine; and by consideration of its effects upon society generally. The experimental subject must not be exposed to excessive asks, and the consent of the patient (or the appropriate guardians) is required. But *prima facie* such activity is permissible: as Pope John Paul II suggested in 1982: "A strictly therapeutic intervention whose explicit objective is the healing of various maladies such as those stemming from deficiencies of chromosomes will, in principle, be desirable, provided it is directed to the true promotion of the personal well-being of the person."

Germ-Line Gene Therapy

In germ-line gene therapy (GLGT) reproductive cells are modified by directly or indirectly inserting some therapeutic gene into, or by removing some defective gene from the egg, sperm or embryo. GLGT affects future generations, but this is not in itself an objection to it: for many things we do, from marrying and having children naturally, to using up resources, polluting the environment, leaving fine works of art or increased knowledge to posterity these things affect future generations, whether for better or worse. There would seem to be no reason in principle (even if in practice the attempt might always be too dangerous) to attempt to confer upon future generations the unambiguous benefit of freedom from some genetic disorder. Indeed some people would argue to the contrary: that one would need very good reasons not to seek to confer such a benefit upon future generations. If the purpose of medicine is the restoration of health and the prevention of ill-health, then it is very much a medical task, as well as one of ordinary human beneficence, to seek to ensure the genetic good health of our children, and our children's children, to a thousand generations.

Some writers remain intractably opposed to germ-line interventions on the basis that this is an attack on human nature or dignity. In 1982 the Council of Europe proclaimed a right to an intact genetic heritage in the name of human dignity and expressed strong reservations about any GLGT. The German Enquete-Kommission recommended in 1987 that the Bundestag forbid all germ-line interventions

under the criminal law. In 1988 eleven European medical research councils jointly stated that "GLGT, for the introduction of inheritable genetic modifications, is not acceptable". And in 1991 the French Comité Consultatif stated that "any attempt deliberately to alter the genome of germ cells and any gene therapy involving the risk of such alteration are absolutely prohibited".

Other writers, and sometimes the same writers, would allow GLGT in certain strictly confined circumstances. The Council of Europe, for instance, has more recently (1986) qualified this opposition with a clause "except for therapeutic purposes" where the therapy is aimed at correcting pathological hereditary characteristics. The Inuyama Conference of 1990 declared: "The modification of human germ-cells for therapeutic or preventive purposes would be technically much more difficult than that of somatic cells and is not at present in prospect. Such therapy might, however, be the only means of treating certain conditions; so, continued discussion of both its technical and its ethical aspects is essential. Before GLGT is undertaken, its safety must be very well established, for changes in germ-cells would affect the descendants of patients."

The problem is, of course, the risks. Animal studies have demonstrated a high incidence of mortality and abnormality in the immediate subjects of germ-line interventions, to say nothing of their progeny. Even if the risks of such therapy were to diminish so as to justify treatment as far as the immediate subject were concerned, there might still be undue risks to his or her descendants, at least some of whom would have been healthy were it not for the treatment of the ancestor. Nonetheless such risk-taking is not to be ruled out of court absolutely: We already take many risks with patients' lives in medical situations and many more risks with the lives of others in everyday life; we also sometimes take risks with the lives and health of future generations, as when we give drugs to pregnant women or use nuclear power. Laboratory models for the genetic modification of non-human mammalian embryos have been developed, phenotypic alterations are possible, the planned transmission of genetic characteristics is also possible, though less predictable, and on this is subject of considerable current research. What application it might have to human beings in the twenty-first century is hard to predict. But on the face of it low-risk GLGT would be preferable to the continued transmission of the more horrible genetic disorders or the disposal of IW carriers or the induced abortion of *in utero* carriers.

In assessing any such future application of GLGT, one must consider: the benefits, burdens and risks of both treatment and non-treatment for the patients and their progeny; whether the proposal is consonant with the profession and vocation of medicine; and what its effects will be upon society generally, including the effect upon its fundamental values.

One might summarize the benefits and burdens as they appear in the literature, as follows (after Juengst 1991). The benefits of GLGT are:

- Medical utility and necessity: GLGT offers a true cure or palliation for many genetic diseases, and sometimes the only effective way of addressing those diseases;
- Prophylactic efficiency: by preventing the transmission of disease genes, GLGT would obviate the need to perform costly, risky somatic cell gene therapy in multiple generations, and would reduce abortions; and
- Respect for the autonomy of patients and scientists: we should respond to the reasonable requests of prospective patients, and to the reasonable research interests of individual scientists and scientific community.

Amongst the common arguments against GLGT are:

- Scientific uncertainty and clinical risks: GLGT experiments would involve too many ineliminable and unpredictable long-term iatrogenic risks to the transformed subjects and their offspring;
- Slippery slope to enhancement and eugenics: GLGT techniques would open the door to attempts to enhance human traits through germ-line intervention, which could exacerbate problems of social discrimination based on those traits;
- Lack of consent: GLGT experiments would involve research with human embryos and effects upon their offspring, effectively placing them in the role of unconsenting research subjects; and
- Integrity of genetic patrimony: GLGT techniques would violate the rights of subsequent generations to inherit a genetic endowment that has not been intentionally modified and possibly cost valuable genetic diversity for the human race as a whole.

Designer Babies, Selection and Negative Eugenics

There are new methods of making designer babies. We no longer have to rely on the genetic roulette of the couple's egg and sperm, or even the more effective but still rather ham-fisted way of designing babies by using hand-picked donors. A far more effective way is to test the babies we already have, either while they are in the laboratory petri dish or in the womb, to see if they have the characteristics we want or don't want. If they have characteristics we want, we can transfer them from test-tube to womb or leave them in the womb to go to term. If they don't we can flush them down the sink or abort them. In the previous chapter I noted that in many countries this is already commonly done for certain handicaps and that the list of those handicaps is growing, partly as a result of increased technical capacity to identify more and more of them, more and more accurately; and partly as a result of the line moving as to which handicaps are regarded as incompatible with worthwhile existence.

HGP has enormous implications here. Will people abort their children if they discover they have a gene they don't like? Sex is now such a handicap in some countries and in some families: so-called 'female sperm', female lab embryos and female unborn children are 'screened out' in their thousands, just for being girls when their parents want boys. One recent American poll found that 11% of couples would abort a foetus merely for having a predisposition for obesity. And the more of these things we can test for, the more undesirables we can dispose of in the laboratory or abort in the womb.

The National Academy of Sciences has reported that already people are losing their jobs and health and life insurance because they or their spouse or their yet-unborn or yet-unconceived children are thought to have a genetic predisposition to some condition. So the social pressures on parents to produce the perfect child and abort any imperfect ones are already there. And they are likely to grow.

Indeed the tune is already close when parents will be made to feel irresponsible for not 'planning' their children, and planning will mean not only how many children (or should I say: how few children) and how spaced, but also with what characteristics. A couple who choose not to have a test for, or not to abort a child with, say, spina bifida, will be regarded as backward and superstitious, even selfish and cruel, and perhaps even criminal. And as Stuart Campbell, Professor of Obstet-

rics and Gynaecology at Kings College Hospital, London, said: 'There is a real worry that people will in future say to a seriously handicapped person: 'Why weren't you terminated?... and cut their healthcare, social welfare, etc.'

Recently doctors at the hospital in the university in which I was working were presented with a couple both of whom suffered from dwarfism. The mother was pregnant and after genetic counseling she was given a genetic test to see if her child suffered the same handicap as she and her husband. Given the high likelihood that the child would suffer this condition, you can imagine the satisfaction of the genetic screeners and counsellors when they were able to report to the couple that their baby was perfectly healthy. The problem was: at this point the couple declared that they wanted an abortion; they wanted only a dwarf child. The doctors were aghast: despite long experience of effective abortion on demand in Britain, they had never before faced a case where a child was to be aborted specifically because she or he was normal!

The case raises all sorts of questions even for those who are committed to abortion on demand. What is handicap and what is health? Is handicap socially constructed? Are we entitled whether as parents or as societies to decide what handicaps are sufficiently serious to warrant the death of the child, whether in the child's supposed best interests or in our own?

There is a joke that when God made man he was only joking; that he had to have a second go, and his new improved model was Eve. Yet we know that there are cultures, not so far away from here, where a child's being female is regarded as a great disaster. India has recently moved to ban genetic sex testing of unborn children with a view to aborting the girls: for this practice has resulted in female to male ratios of 4 to 5 and worse in some areas of India. Genetic testing has become a new tool for the oppression of women East and West.

Recently the world commemorated the fiftieth anniversary of the liberation of Auschwitz: the most notorious, the most deadly of the Nazi concentration camps and gas chambers. Jews were the principal targets; but there were others. The most prestigious medical profession in the world colluded with Nazi eugenics in identifying and killing mentally handicapped adults, those with misshapen ears, bed-wetters, homosexuals, 10,000 babies and children with a variety of disorders,

and a wide group of the supposedly genetically ('racially') inferior. They were judged a danger to the gene pool, as well as useless eaters taking resources from the genetically superior.

There are many lessons yet to be learnt from that experience. Consider two recent articles in *Lament*, the newsletter of the Los Angeles chapter of Mensa, the exclusive club for people with very high IQs. Speaking of the plight of the homeless, the physically infirm and the mentally handicapped, Jason Brent, an attorney, wrote "Society must face the concept that we [should] kill off the old, the weak, the stupid, the inefficient."

Another Mensa member, Jon Evans, wrote about the physically and mentally disabled: "A piece of meat in the shape of a man but without a mind is not a human being", nor is someone whose "body is deathly ill or damaged by accident" (*International Herald Tribune*, 31.1.95, p.4). And even better than killing people is preventing them altogether. Who decides which genetic qualities warrant death? Who decides which qualities are to be encouraged and which discouraged? On what basis? And in whose interests? The sad reality is that the eugenic ideology lives on, in all sorts of ways, even among some of the most respectable scientists, lawyers and academics, and HGP offers some powerful new tools for its armoury.

Prenatal 'selection', i.e. laboratory disposal or uterine abortion, and negative eugenics by abortion, are incompatible with respect for the dignity of the human person and with fundamental principles of common morality and medical ethics. It is family planning by homicide, social engineering by genocide. Killing an innocent, defenceless human being, even one who is very young, handicapped and unwanted, is intrinsically evil and always a harm to the victim, those complicit in the killing and the wider community.

Designer Babies, Enhancement and Positive Eugenics

Effective or enhancing interventions are those aimed at improving a person's health, span of life, or other genetically-affected characteristics beyond the range of normal healthy function. Some people seem to regard this as immoral *per se*, because it interferes with nature. But our relationship to nature is, as I have already noted, more complex than that and we commonly and quite properly intervene to improve on nature—whether by using cosmetics or surgery or drugs or exercise or

diet or vitamin supplements or special education— and not just to make ourselves fit and healthy, but in some cases to make people rather more fit and healthy or beautiful or athletic or intelligent than is normally the case.

Such enhancing interventions may very well not be a part of the practice of medicine which, after all, properly directs itself to the restoration and maintenance of normal health, and the alleviation of distressing symptoms of below normal health. But that they are not proper to medicine and to the health professions does not mean that such enhancing interventions are wrong.

Designing our babies or our populations by aborting those with the wrong genetic characteristics may seem rather primitive in the future: for the time may come when we will design our babies directly, by introducing genes for preferred characteristics such as hair colour, intelligence and the like.

We already engage in some positive genetic design in plant and animal husbandry. More and more sophisticated genetic engineering of this positive sort may be possible in our life time. Oxford University philosopher Jonathan Glover looks forward to the day when we will pick the eye colour and personality of our children from the reproductive supermarket shelf, American theologian Joseph Fletcher to the day when we can design role-related people (e.g. people with extra lungs, or limbs, to help with certain jobs). The potential for racist eugenics, breeding in and breeding out certain desired or undesired characteristics in whole populations, and for creating and sustaining a caste system of elites and inferiors, will grow enormously.

Some writers have argued that while we might properly decide to make such improvements upon nature in ourselves or our own children, to do so in strangers such as our distant future relatives is more problematical. Unlike choices we make which affect the environment of strangers (and these are serious matters too), technological interventions which affect the psychophysical structure of strangers, the very kinds of beings they will be, and not merely as a therapeutic or preventive measure but rather as an attempt by one group to 'improve' another, are an unacceptable intrusion upon the rights of those strangers not to be manipulated in so fundamental a way. Would we consider simply picking strangers off the street in order to make improvements to their looks, their intelligence, their physical size, etc.?

Avoiding Reductionism

Even among Christian writers about HGP, let alone among the secular enthusiasts, there is a dangerous tendency to reduce the human being or human identity to the genome. But a richer philosophical and theological anthropology is required, one which takes an integral view of the human being, body and soul, genetic and somatic, psychological and spiritual. We are much more than our genes, however important they are as organs of our development. Indeed, there is more to our genetic than our genome, more to our biology than our genetics, and more to us than our biology. Yet leading geneticists and their journalistic publicists are almost invariably genetic determinists.

Pope John Paul II (1983) has noted that

the fundamental attitudes that inspire the interventions of which we are speaking should not flow from a racist and materialist mentality aimed at a human well-being that is in reality reductionist. The dignity of the human being transcends his or her biological condition. Genetic manipulation becomes arbitrary and unjust when it reduces life to an object, when it forgets that it is dealing with human subjects, capable of intelligence and freedom, worthy of respect whatever may be their limitations; or when it treats these persons in terms of criteria not founded on the integral reality of the human person, at the risk of infringing upon their dignity. In this case, it exposes the individual to the caprice of others, thus depriving him or her of autonomy.

As an 'expert in humanity' with a mission to serve the civilization of life and of love the Church takes the middle ground between the extremes of applying genetic technology simply because it is available, and rejecting responsible and humane scientific progress and therapeutic treatment of genetic disease simply because they are novel or artificial.

Fundamental to any Christian assessment of the application of the results of HGP will be principles such as: accountable stewardship; the preservation or protection of the nature and destiny of humankind; respect for life from conception; equal care and respect for persons; and charitable justice in the distribution of resources (Cassidy & Pellegrino 1993).

Conclusion

HGP is understandably the source of great excitement in the scientific community, in biobusiness, and beyond. It is a source of great hope for medicine, potentially the beginning of a new era of therapies. But I suspect that the science is marching ahead so fast, that ethics, theology and law have been unable to keep up. And by 'keep up' I don't mean 'approve': rather I mean *unable* to provide reasoned, critical, humane reflection on the implications and advisability of these developments. And not simply unable: often enough, ethics and law have been deliberately *disabled* by those with power and knowledge, disenfranchised by not being privy to the developments or only on condition of silence and sycophancy. A result has been that contemporary scientific communities enjoy a sophistication in their scientific knowledge unparalleled by any generation, but a moral wisdom which is stunted and unequal to the challenge of the science. Adult science is mismatched with childhood ethics.

I cannot lay bare all the ethical challenges that arise and are deserving of consideration. In another place* I noted some concerning the reproductive technologies which I think recur here: a profligacy with early human life; a certain mechanistic glibness rather than awe before the mystery of life in its transmission; a commoditized view of the embryo; powerful consumerist assumptions; the technological imperative that holds that if a thing can be done it should and must be; a profound pragmatism which pays little heed to the moral and other costs of achieving apparently good results.

One source of difficulty here is that most prominent molecular biologists have a financial stake in the biotechnology business—whether as founders, directors, officers, stockholders or employees. This will inevitably lead to conflicts of interest. Already there is a fight going on regarding patenting the human genome, and it is a fight about money. One more distorted value which I think is lurking under much HGP thinking is a 'dark ages' view of handicap that says the handicapped are better off dead, better off never born. Nowadays we should realise just how relative disability is: if HGP teaches us nothing else,

* See "The Brave New World of Reproductive Technologies" in *Philippiniana Sacra*, 89 (1995) 277-291.

it should teach us that no one is perfect. Many 'handicapped' people, with inspiring determination, accommodate to or overcome their disabilities; and much can now be done to assist them in this. No doubt some parents will be unable to cope and might have to give their handicapped child up to the care of others; others, with support from individuals and the community, will take on this heroic but often very satisfying task. The disabled child can no doubt put great strains on a family's generosity and communities are often too slow in helping; but the disabled can also make a great contribution to a family and society. But even if they do not, who are we to say that they should be screened and 'selected out' by a genetic search and destroy mission? Is physical or mental perfection to be a prerequisite for human rights? Who are we to make such a judgment? And what do we make of *ourselves* when we do?

Disability is not the main cause of unhappiness in its victims: rather it is often the lack of support and the condescending, fearful and discriminatory attitudes of those who think the handicapped are better off dead which causes the greatest loss of self-esteem. Despite their limitations, with love and support, handicapped people have as much potential to be happy as anyone else.

HGP is the source of many hopes and fears. I shall leave the last word to the hero of Manila of only a few days ago. Our genome adventure, as Pope John Paul II (1983) has pointed out "covers on the one hand adventuresome endeavours aimed at promoting I know not what kind of superman and, on the other hand, desirable and salutary interventions aimed at the correction of anomalies such as certain hereditary illnesses." It remains "ambiguous and should constitute an object of our true moral discernment."

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