

# The Advent of the Genetic Quotient

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This article is intended to be both an analysis, and also an account: that of a generation of young citizens, to which I belong, which is both enthusiastic about and worried by recent advances in genetics. In the modern world mind set evolves very rapidly. In the late 1960s women demanded 'a baby when I want!' The right to contraception followed. Then, in the early 1970s, another slogan was heard: 'a baby if I want.' Shortly afterwards, a woman's right to abortion was recognized. Now, new demands are increasingly being synthesized as: 'a baby of the kind I want.' The spectre of eugenics is slowly and insidiously being reborn at the heart of democracy.

## Defining eugenics

So what is eugenics? In 1883 Sir Francis Walton, a cousin of Darwin, created the term 'eugenics', whose etymology signifies 'well-born'. The eugenic movement was born from a myth, that of the degeneration of humanity<sup>1</sup>. In order to purge humanity of its imperfect specimens, eugenics envisaged the remedy of selection of people according to normative and arbitrary criteria.

Traditionally, a distinction has been made between two types of eugenics. 'Positive' eugenics was aimed at improving humanity by advocating better births; the method it used was selective mating (*Lebensborn* [fountain of life]). 'Negative' eugenics, on the other hand, was aimed at limiting the decline of humanity by preventing 'inferior' births. The methods used were sterilization and euthanasia (for example, sterilizations in Sweden and the United States of America, and the Final Solution in Nazi Germany). When eugenics is mentioned, everyone immediately thinks of negative eugenics in the Third Reich. I shall attempt to show how eugenics is reappearing today in 'a white coat' by way of genetic medicine.

## Treatment or selection?

Let us take the example of artificial insemination (IVF). In the case of male infertility, it is sometimes necessary to inject a sperm into an ovum to fertilize it (ICSI – intracytoplasmic sperm injection). The male gamete is introduced directly into the ovum with the aid of a micro-pipette. This produces an embryo and the couple are able to overcome infertility, thanks to ICSI. But although the technical problem is resolved in this way, it immediately opens up a gaping hole in ethics.

In fact, those who practise ICSI have suddenly realised that, if the father's sperm is sterile, any boy conceived will also suffer from sterility. More to the point, doctors have

increasingly become aware that, in order to correct this infertility, they will in all probability have to extend the same treatment from generation to generation.

In other words, this technique – which was thought at first to be beneficial – will in the end reproduce the faults that people have been trying to correct. So what is to be done? Why not manipulate the father's sperm directly in order to make him fertile and, thus also making all his descendants fertile? To put it another way, why not practise gene therapy?

This question will be asked because it seems perfectly logical. Although condemned at the moment for 'ethical' reasons, the debate on gene therapy is not over, just postponed. Doubtless it will be revived very soon. So what? Surely it is more logical to treat a complete germ line at the same time rather than to have to return to the same treatment for each generation?

There is another possible suggestion: instead of correcting defective sperm, why not just select perfect sperm? To put it bluntly, genetic tests could be applied not just to people and embryos: they could also be used to examine gametes before fusion. This would involve a thorough analysis of the premarital health check, applied, not to the marriage of people, but the fusion of gametes.

If it were to be examined closely enough, the ICSI example would reveal a change of direction: when ICSI was first envisaged, medicine merely wanted to remedy infertility. It ended up with doctors trying to bring about 'standard births'. The issue is no longer one of treating some defect or other with a technique or a therapy. From now on the logic of reproductive medicine treats it as being predictive and preventive: selection rather than treatment. This selective logic operates according to criteria based on evaluative tools: genetic tests.

## **The Genetic Quotient**

What do we mean by genetic tests? Mapping the human genome has enabled us to create DNA chips capable of analysing the imperfections of our genetic inheritance. These chips are used in the manufacture of 'genetic tests' which analyse thousands of mutations in a single individual. At the moment predictive medicine has about 650 genetic tests at its disposal. By 2010 it will have nearly 5000.

These tests are grouped together in diagnostic units known as 'genetic kits'. This battery of tests is preparing the way for what I call the 'Genetic Quotient<sup>2</sup>'. What does this mean?

Just as the Intelligence Quotient tests measure the performance of the intellect, so the Genetic Quotient too could be determined by these tests which measure the quality of the genome. In other words, the more harmful mutations included in an individual's genome, the lower his Genetic quotient would be.

From that point onwards, medicine would have at its disposal a scientific method for quantitatively evaluating the biological purity of a person, even before they were born. By consulting a reference scale, genetic profiles could be positioned either side of a statistical median. We would then run the risk of establishing a health hierarchy, distinguishing between the 'gifted' and the 'less gifted'.

A combination of reproductive and predictive medicine has already brought about some attractive temptations. Basically, artificial reproduction necessitates the production

of a number of embryos which are stored *in vitro*. Before they are implanted in the womb, neither parents nor doctors hesitate to check their respective Genetic Quotients by means of pre-implantation diagnosis to select the best eggs. Indeed, what is the point of treating defective embryos now direct selection of perfect specimens from the neighbouring test tubes is possible?

*An example: pre-implantation diagnosis of Duchenne muscular dystrophy*

The first pre-implantation diagnosis was done in 1999 in the Antoire-Béclère Hospital in Clamart, the first authorized centre in France, and related to a case of Duchenne muscular dystrophy. This degenerative disease of the muscles, which is always fatal, only affects boys within the same family. Girls are carriers of the disease but do not suffer from any of the symptoms and live a completely normal life.

Couples who are aware of cases of muscular dystrophy in their family tree, decide to make use of ZIFT (zygote intra-fallopian transfer) with pre-implantation diagnosis to make sure that they do not give birth to a boy affected by muscular dystrophy. The diagnostic tests reveal that the embryo *in vitro* is a girl, and thus that this child will not suffer from muscular dystrophy. Consequently, one would expect the medical team to decide to let the baby be born. But this is not the case. The doctors have decided that it would be preferable 'not to let the baby be born', their reason being that, although not suffering from muscular dystrophy herself, the girl is a carrier and could transmit muscular dystrophy to future generations.

Looking at this example from a sufficiently detached viewpoint, what do we see? To begin with, the medical team intended to terminate only those embryos which were affected with the disease; in the end, the healthy carriers were also terminated. To put it another way, prevention of certain handicap became prevention of possible handicap. This example reveals a new definition of the word 'prevention'. Before 'prevention' meant 'avoiding the appearance of a disease'. Now 'prevention' means 'avoiding the appearance of a diseased person'.

And so we come back to the very foundation of our questioning: surely the aim of predictive medicine is to predict the genetic quality of future human beings? If their Genetic Quotient turns out to be below average, would not preventive medicine be tempted to terminate this future human being in order to replace them with another? Thus the saying 'Prevention is better than cure' runs the risk of becoming 'Destruction is better than cure'. Because, in effect, what is the point of treating the human embryo?

### **Sensible birth control**

Some people claim they want to provide treatment for the human embryo, considering it to be 'the smallest patient' . . . If this wish seems benevolent *a priori*, putting it into practice seems to be tragically illusory, for three reasons.

1) First, the success of treatment by gene therapy is still less than conclusive and its medical outcome is uncertain.

2) Next, when the techniques are mastered, these treatments will remain expensive and thus unwelcome in a context which is trying to limit health costs.

3) Finally, as a counterpoint to these two arguments, an alternative solution exists which is practical and appealing, and which cancels out the economic and technical disadvantages: the selection of embryos.

Selection of human eggs is simultaneously economic, effective and easy to carry out and offers unequalled health benefits. This form of birth control is intended to be rational. Indeed, it fulfils all demands: economic (cost control), scientific (use of efficient techniques) and ethical (because it is supported by freedom of 'parental choice'). By means of this triple justification we are witnessing the medical rehabilitation of eugenics which, by turning its back on ideology and racism, prefers to be seen as a pragmatic and rational choice. In a word, eugenics is trying to become 'ethical'.

### **Genetic quality control**

Thanks to the tools of the technique, the spectre of purification of the human race has insidiously been reborn under a new guise, which accounts for the difficulty of identifying it and thus of combating it. Indeed, eugenics is no longer violent, totalitarian, and promoted by the State but a private and freely allowed part of an individual experience: that of having a baby.

This is a new eugenics whose immediate effect could be genetic quality control rather than genetic manipulation as had been thought up till now: quality control dependent on the overall score of the Genetic Quotient, whose scientific objectivity could sanction and serve the discriminatory consequences of social selection. What examples are there of genetic ostracism?

*Recruitment of employees to a business:* why recruit an executive for a stressful position if his Genetic Quotient indicates that he is a suspected cardiac risk?

*Selection of university students:* why offer a grant to a candidate whose Genetic Quotient reveals a strong predisposition to leukaemia, casting doubt over whether they would be able to finish their studies?

*Investigations into those wanting to take out an insurance policy:* why insure clients whose genetic degeneration indicates serious medical liabilities in the short term?

In this way, the Genetic Quotient could progressively install a medical hierarchy at numerous levels on the social scale, thus affecting the very principle of equality of citizens in a democracy.

### **Children as consumer goods**

What about the law? Does it present solid obstacles to abuse? The Code of Public Health (Article L 152–2) stipulates that 'medically assisted reproduction is intended to meet a couple's *desire to become parents*. (. . .) It can also be used to *prevent the transmission of a particularly serious disease to a child*' (my italics).

The expression 'the desire to have a child' conveys the logic of our times: 'As parents, we demand a perfect child!' Surely there is a danger that, as predictive techniques become more refined, couples will increase their demands and not tolerate any imperfections? The 'clients' are becoming increasingly difficult: they refuse to accept the slightest abnormality, such as a harelip<sup>3</sup> or hexadactylism, which can be repaired by surgery in exchange for a few scars.

No more neonatal 'makeshift repairs', no more 'after sales service'! The demand to become a parent is a response to a medical offer: the guaranteed production of genuine little angels! For from now on supply and demand will feed off each other according to consumer logic. Predictive medicine will have to offer complete satisfaction to its clients. Beware of mistakes and incorrect diagnoses which do not reveal *handicaps*: doctors are now brought before the courts and made to pay damages.

### Precautionary eugenics: the 'Perruche' affair

The 'Perruche'<sup>4</sup> ruling confirms – by way of precedent – the advent of the Genetic Quotient. By awarding damages to someone handicapped from birth, the Supreme Court of Appeal described their 'non-standard' life as 'a loss which deserved compensation'. By means of this judicial decision, society has given its verdict on 'a man not subject to quality control': it is not in his interest to live.

This judgement threw all the associations for the handicapped into turmoil: what would happen if all those who were paralysed claimed damages from their parents and the doctors, as if they were responsible for their suffering? In reality, the analytical grid of the 'Perruche' affair deals with three complementary lines of reasoning based on the direct interests of each party involved:

1) *The parents*: it was in their interest to use the maximum number of genetic tests to prevent any handicap and thus maximize the Genetic Quotient of their child.

2) *The doctor's insurance company*: it obliged the doctor to run genetic tests to minimize the risk of having to compensate the patients if a handicapped baby was born.

3) *The doctor*: until now he had been held responsible for the means, but from now on he will be responsible for the result: the child should be born 'within the norms' or else the doctor will be liable to pay compensation. Faced with this alternative, the doctor will decide that it would be wise to carry out an abortion if there is even the slightest doubt, and will increasingly turn to a utilitarian logic: that of eugenics as a precaution.

These three lines of reasoning, dictated by the immediate interests of the protagonists, converge towards the same end: the advent of eugenics and the Genetic Quotient. The Perruche ruling has finally brought about the realization of an alarming vision predicted nearly forty years ago:

No newborn infant should be recognized as being human before passing a certain number of tests concerning its genetic endowment. If it does not pass these tests, it will lose its right to life.  
(Francis Crick, co-discoverer of the structure of DNA, Nobel Prize for Medicine, 1962)

More generally, this account reveals the influence of science on ethics. In effect, the successes of molecular biology during the last forty years have contributed to the revelation of man himself, reducing him to his genome, to his programme, and thereby, in a certain sense, dehumanizing him.

## **Beliefs**

I often wonder about my approach. Why is a young man of my generation, and one so passionate about biology and philosophy, worried about the progress of the age? Surely at my age, I should be enthusiastic about the marvels of technology?

Should I be hostile to progress? Can a lover of science be hostile to progress? As far as large-scale therapeutic hopes are concerned: how can one not be aware that biotechnology may be able to find cures for dreadful scourges, like cancer? How could one dare to curb such hopes? Although the outcome is unquestionably good, the means of achieving it make my blood run cold.

People will perhaps find my article disturbing. Nevertheless, while tomorrow is now being discussed, I want to think of the future. I am trying to adopt a long-term vision: by analysing what may happen, it is my aim to examine the limits of reality in order to catch a glimpse of the horizons of predictive medicine. This medicine is already making great strides towards the selection of human embryos. In order to avoid destroying defective embryos, will we not be making direct attempts to produce perfect embryos? By increasing the number of experiments on embryos, without doubt one day – through trial and error – a genome of extremely high medical quality (Optimal Genetic Quotient) will be obtained. Will it not then be very tempting to copy it in order to be able to offer this perfect model for every birth? Reproductive cloning could turn out to be the culmination of this medicine which is modestly described at the moment as ‘predictive and preventive’.

I can already hear reproachful critics muttering: ‘stop spreading doom and gloom!’ However, I am not a pessimist: without an answer I am just anxious and unsettled. Like Hans Jonas, I think that ‘Misfortune is prophesied in order to avoid it materializing<sup>5</sup>’. Yes, it does worry me to note that neither the law nor ethics seem able – for the moment – to hold back the advent of the ‘bio-power’ analysed by Foucault<sup>6</sup>, and which is taking shape today as a result of the advent of the Genetic Quotient.

Fuelled by extensive economic interests, this ‘bio-power’ has met with little resistance. The law has shown itself to be a very flimsy obstacle. It would seem that that which was banned in 1994 – the creation of human embryos for experimental purposes, recourse to genetic tests, patents on the human genome<sup>7</sup>, cloning described as ‘therapeutic’, etc – is now being allowed in practice.

## **What is the purpose of ethics?**

How have we reached this point in so short a time? Surely the specific role of ethics is to prepare the law through reflection on moral and social values? That role seems to have devolved to it *a priori*. On the other hand, I think that the function of ethical barriers is not to prevent shifts occurring (as might be thought), but only to postpone them for a while in order to prepare society to accept them.

The progress of technology has been too precipitous. It causes shock and fear. Ethics seems only to consist in slowing down the excesses until the citizens' state of receptivity is capable of meekly accepting what, before, would have been denounced as being contrary to ethics.

The ethics of broken proscriptions plays the roles of solvent, thinner and sweetener, designed to create adhesion in the masses. Time creates a lever for acceptance. Little by little, public opinion grows accustomed to what it had condemned at the moment of discovery, and hostility slowly weakens. Time fractures the fixed nature of benchmarks and values dissolve in it like sugar in water. To return to Nadine Fresco's metaphor: 'ethics is a zoological cold frame!<sup>89</sup>

Nor do I think that ethical inspiration in our country, France, has been generated by worries about caution. On the contrary, I think that ethics is born of impatience. In effect, impatience precipitates the application of technology as a matter of urgency. The 'logic of the lesser evil' is chosen, but nothing, apart from impatience, imposes an alternative between two bad options. Ethics presents itself with insoluble choices which it has fostered itself. These choices are fertilized by the voracious impatience of living at the instant of technical innovation. Then impatience begets ethics, that is, the guarantee of carelessness. I often inveigh against the prologue to Zarathustra, in which Nietzsche writes:

Look, I show you the last man. ( . . . ) His species is indestructible, like the aphid; the last man is the one who will live the longest. 'We have invented happiness', say the last humans and they screw up their eyes.

(Nietzsche, *Thus Spoke Zarathustra*, Prologue, §5)

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Translated from the French by Rosemary Dear

## Notes

1. A. Carol, *Histoire de l'eugénisme en France (History of eugenics in France)*, Paris, Seuil 1995.
2. The 'Genetic Quotient' is a new concept which I introduced and analysed in my doctoral thesis in the Faculty of Pharmaceutical and Biological Sciences in Paris. See G. Bénichou, *Le Quotient génétique. Vers une hiérarchie sanitaire des génomes humains? (The Genetic Quotient. Towards a health hierarchy of the human genome?)*, submitted in November 1999, in the Faculty of Pharmaceutical and Biological Sciences in Paris (UPV) (board of examiners composed of J. Testart, J. Toubon, D. Durand, D. Bégué, A. Baudart, D. Lagarde).
3. M. Serres, A.-R. Chanchole, *A visage différent (With a different face)*, Paris, Hermann 1997.
4. Supreme Court of Appeal ruling, 17 November 2000.
5. H. Jonas, *Le principe responsabilité (The prime responsibility)*, IV, 5, trans. J. Greisch, Paris, Cerf 1997.
6. M. Foucault, *Histoire de la sexualité, La volonté de savoir (History of sexuality, The desire to know)*, Paris, Gallimard 1976, p.184.
7. G. Bénichou, 'Comme maîtres et possesseurs de la nature', une réflexion philosophique sur la privatisation du génome humain' ('"As masters and possessors of nature", a philosophical reflection on the privatization of the human genome'), in *Les Cahiers du CCNE (CCNE Notebooks)*, No.25, September 2000, p.13–19.
8. N. Fresco, *Le clonage humain (Human cloning)*, Paris, Seuil 1999, p.189 *et seq.*