KURT BAYERTZ AND KURT W. SCHMIDT

TESTING GENES AND CONSTRUCTING HUMANS – ETHICS AND GENETICS [1]

Gene technology has had dramatic effects on the field of human medicine. Many of the latest diagnostic and therapeutic procedures are based on gene technological methods, and further progress in this field is expected in the near future. Above all, scientists are convinced that medicine will be revolutionized by the Human Genome Project: both at a theoretical level, involving the understanding of diseases and their geneses, and at a practical level, involving the development of more effective strategies to combat those diseases. They believe us to be at the beginning of a 'molecular medical era' which, as a new 'paradigm', will be analogous in fundamental importance to the 16th century paradigm of anatomy or the 19th century paradigm of cellular pathology.

This far-reaching importance is due to some specific features of gene technology which distinguish it from other technologies, and which are manifested in what may be called its 'depth' and its 'breadth'. On the one hand, gene technology *deeply* invades human nature and living matter generally. On the other hand, it is *broadly* applicable to many different areas of biomedicine and many different aims. Gene technology can be used as a tool or a methodology for (a) biomedical research (basic and applied); (b) diagnostics; (c) therapeutics; (d) industrial or pharmaceutical production. There seems to be no part of the biomedical field for which gene technology is not – at least potentially – of importance.

This 'revolutionary' potential has led gene technology to become a major target for ethical reflection. While there can be no doubts that gene technology will solve many biomedical problems, it is just as transparent that it will also create new ones. This in turn raises many ethical questions, some of which have, in the past few years, already been cause for controversy. These issues cover a broad spectrum which may be divided up into (at least) the following four types:

1. *'Heavy questions', e.g. "Are human beings entitled to uncover the secret of life?" or "Are human beings entitled to 'Play God'?"*
2. *Conceptual problems, e.g. "What meanings may terms like 'disease' or 'health' acquire at a molecular level?" and consequently "Can a precise distinction be made between therapy and enhancement?"*

G. Khushf (ed.), Handbook of Bioethics, 415–438.

3. *Social problems caused by some unwanted side-effects of gene technology, e.g. "How will the proliferation of genetic data influence the self-image of individuals and of the human race in general?" or "Will the widespread use of prenatal diagnostics lead to a decreasing tolerance towards handicapped people?"*
4. *Problems resulting from possible technological risks, e.g. "Should gene therapy be restricted to severe and fatal diseases?" or "How can the reliabilty and validity of genetic tests be guaranteed?"*

It would obviously exceed the limitations of the present paper to analyze or evaluate these different risks and weigh them up against corresponding benefits. Instead, we should like to focus on two of the more fundamental ethical issues surrounding the impact of gene technology on the core of the biomedical enterprise: diagnostics and therapy. Problems of research and of pharmaceutical production will play no role in the following considerations.

In Section I we shall discuss molecular genetic diagnostics and some of its (potential) consequences for the *autonomy* of individuals. The concept and the principle of autonomy are of outstanding importance for the recent bioethics 'paradigm.' But doubts have arisen as to whether additional options gained as a result of biotechnological development can really be seen as benefitting individual autonomy. It is not only a case of individual autonomy *always* being under threat (a principle exists for this very reason, with the explicit intention of protecting it); we will also discuss the hypothesis that the further development and comprehensive application of genetic diagnostics will *structurally* question some of the prerequisites underlying the principle of autonomy: this holds true at the conceptual and social levels.

The main topic of Section II is the *constructive* potential of this new technology. From its beginning, proponents have promised and opponents have warned that gene technology will lead to a deep change in the essence of the medical enterprise, namely a transition from repair to design. This prospect gives rise to a whole series of ethical problems, which we have summarized in the two categories: (1) "Where to draw a line?" and (2) "Why draw a line?". In the final section we return to the concept of autonomy. Although gene technology will provide new options regarding individual self-determination and self-realization, our considerations conclude that this is only one dimension of the development; the other is the price which will inevitably be paid for maximizing the constructive potential of gene technology, namely the autonomy of future generations.

I. GENETIC DIAGNOSTICS AND INDIVIDUAL AUTONOMY

Gene technological diagnostic methods are no longer reserved for the relatively few monogenous hereditary diseases, and are now also being used to detect genetic dispositions for such widespread diseases as cancer or heart disease, as well as some non-hereditary diseases. In so doing, they have expanded beyond the narrower field of human genetics, entering more or less all areas of medicine. In some respects the knowledge gained is similar to that produced by conventional diagnostics, and yet it also differs profoundly. For a long time now there have been intensive and fruitful discussions about the ethical, social and legal implications of this kind of diagnostics; some detailed criteria for its practical application have been drawn up as a result (cf. Andrews *et al.*, 1994; Annas and Elias, 1992; Cook-Degan, 1994; Holtzmann, 1989). We shall not present those results here, but concentrate instead on the implications potentially arising from a structural limitation of individual autonomy.

A. The superindividual character of genetic knowledge and limits of the Lockean paradigm

A special feature of genetic knowledge is that in many cases it is not only knowledge about an individual person, but also knowledge about a more or less large number of other persons. This is due to the fact that genes and genomes are essentially *superindividual* entities. All human individuals share 50 per cent of their genes with each parent, 25 per cent with each grandparent, etc.; human beings even have most of their genes in common with non-related other human beings. This means that the 'object' of a molecular genetic diagnosis cannot always be reduced to the individual person being tested: the diagnosis often amounts to an examination of certain characteristics of an entire group of people, including some not yet born.

If one assumes – as is widely accepted – that genetic knowledge about a particular person has to be viewed as particularly 'sensitive' knowledge, then difficult ethical problems ensue. Take, for example, Mrs. X, who undergoes genetic testing for hereditary breast cancer. Unfortunately the result is positive and she tells her family about it, horrified. In so doing, however, she informs her daughter about the fact that she too is at an increased risk of contracting this disease. The problem being that her daughter had previously had no idea about this risk, maybe not wanting to have been informed. By exercising her right to know, Mrs. X simultaneously violates the right of her daughter not to know. How are the 'autonomies' of the different persons involved – synchronously and

diachronously – to be weighted when the field of diagnostics ceases to be limited to individuals? The diversity of appraisals that individuals may have regarding these ethical concerns highlights the values involved in determining an appropriate *standard of care* in the context of genetic diagnostics. Idealization (like tailoring disclosure in informed consent to suit the particular patient) fails to attend to the reality of a need for standardization (Parker and Majeske, 1996).

Of course, the problem of unwanted information is not altogether new. Before genetic testing it was also possible, for some people and in some cases, to deduce health risks from family histories: for example, people with several close relatives who have all died of heart attacks relatively young will necessarily have presumed themselves to be at a significantly higher risk. Nevertheless, the progress of genetic diagnostics is changing the situation both technically and ethically. (a) Risks are rapidly being assessed with increasing accuracy; (b) the knowledge pool is growing in size for two reasons: more and more genetic diseases can be tested for, and the number of persons being tested is increasing; (c) previously, genetic knowledge came to light 'spontaneously' and unavoidably, whereas the information arrived at today through gene technology is derived purposefully and consciously; and (d) modern possibilities of data processing, data transport and data storage render information available anytime, anywhere. This raises the ethical question of whether it is legitimate to perform relevant genetic tests when doing so violates the right of third parties to informational self-determination. Or, to put it another way: how are the rights of the persons involved to be weighed up in such a case?

Let us take a look at another aspect of our above example: Mrs. X hears the news that the results of her genetic tests for hereditary breast cancer are positive and decides *not* to tell her family, in particular her daughter. She asks her doctor to handle the matter confidentially. Let us also assume that her daughter would have been extremely glad to have this information in order to plan her life accordingly. Would withholding this information from her then not amount to an infringement upon her right to self-determination? Furthermore, would the daughter even have had the right to remain ignorant and not want to have this information so central to her life (cf. Rhodes, 1998)?

Whilst some people believe that the superindividual character of genetic information must not be allowed to influence the previously individualistic doctor-patient relationship and that issues surrounding the imparting of disclosure, beneficence and medical secrecy must not be allowed to change that doctor-patient relationship, others propose extending the definition of the term 'patient': whereas in the classic individualistic approach the physician has responsibilities towards the *individual* patient (regarding medical secrecy, etc.), in an alternative framework of genetic consulting the 'patient' could be the entire

family environment (cf. Wachbroit, 1993). If, in our example above, this idea of the patient were to include Mrs. X's daughter, then the health professional's informing of the daughter would not constitute a breach of confidentiality. One might even argue that the health professional is not simply *permitted* to inform the daughter, but actually *required* to do so. The moral problem is no longer concern about confidentiality, but now concern about: just who is the patient?

Our interest lies in emphasizing the essentially superindividual character of genetic information and calling to mind the potential limitations which this superindividuality could pose upon individual access to genetic information. According to a widespread view for which John Locke is usually considered to be a source of authority, there is a close connection between the concepts 'person' and 'property'; the 'person' concept includes one's own body, meaning that the relationship between human beings and their bodies may be perceived as a relationship of property: "Every Man has a *Property* in his own *Person*" (Locke, *Second Treatise of Government*, § 27). Genes are beyond doubt part of the human body, and yet in their case one of the central prerequisites underlying Locke's theory is *not* fulfilled: the clear distinction, indeed separateness of individuals and their bodies. Locke could hardly have imagined that access to a part of one's own body could also mean access to parts of another individual's body. It has consequently been suggested that genetic information about any individual be regarded not as personal to that indvidual, but as the *common property* of other people sharing those genes. This would curb individual access to 'one's own' genetic information, thus protecting other individuals.

The Lockean paradigm also reaches its limits at the point where autonomous access of an individual to his or her genetic information affects the rights of an entire group. This problem occurs – whether as part of the *Human Genome Diversity Project* or on the initiative of individual firms – where testing is to be carried out not only on the single genes of single individuals, but on the genomes of entire populations. Some races with genetic peculiarities of interest to researchers decline examination on the grounds of scientific colonialism.[2] Individual race members could almost certainly be won over to participate in such a research program, and the refusal of the majority thus circumnavigated; yet, applying the theory of common property, such use of 'genetic dissidents' would be morally reprehensible. In some countries (e.g. Canada) projects of this kind are therefore only legally permissible if willing individuals can be found to participate *and* if the leaders of the people in question give their consent. Individual rights of access to genetic information are therefore implicitly limited by the essentially superindividual character of that information (Cranor, 1994; Bayertz, 1997).

A similar notion also seems to be behind the *Universal Declaration on the*

Human Genome and Human Rights adopted by UNESCO in November 1997. Here the problem is not discussed in terms of property, however, but in terms of "common heritage." Based on the view that scientific and technological progress plus the new options resulting from it have rendered the human genome a good worthy of protection, this Declaration seeks to establish a path enabling a new balance to be found between the common interests of humanity and individual rights. Article 1 of the Declaration states: "The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity" (UNESCO, 1997).

This "common hertitage" point of view, which over the last decade has been successful in public policy settings, especially in Europe, is deemed by others to be an outdated body of thought from the 19th century, conceptually flawed and socially dangerous. We cannot conserve this 'natural resource' with declarations (e.g. by forbidding interventions in the human germ line) because, from a scientific point of view, the human genome is not a natural object but an heuristic abstraction, like the anatomist's concept of the human skeleton. Our "worries about preserving its integrity for future generations become concerns about the future of an idea, not a natural resource" (Juengst, 1998b). We should pay more attention *to the social context* of future generations than to their *genetic resources*. In the long run, "we should not be concerned about the ones who benefit from gene therapy or enhancement, rather the preeminent need will be to protect those among the future generations 'unfortunate' enough to enjoy an untampered genetic inheritance from the social discrimination and the unfair disadvantages that they could face in living and working with their genetically engineered neighbours" (Juengst, 1998b).

B. The social context of genetic testing

From a medical point of view, genetic diagnostics has two essential advantages over conventional procedures. Firstly, the *predictive potential* is significantly higher: a genetic test is able to establish the risk of contracting a disease long before first symptoms present themselves. Since detecting a risk early provides opportunity for intervention which are often not there at a later date, this is extraordinarly attractive to the medical profession. Secondly, genetic tests are able to function as a vehicle of medical *individualization*, enabling named persons to be attributed with increased risks for particular diseases to a far greater extent than was ever possible before, even including statements about the expected course and severity of disease (cf. Juengst, 1998a). Seen in this light,

individually 'tailored' therapies could well become a future reality.

In many respects this development has to be seen as an achievement: it will provide a chance for medical aid in cases which today are still considered hopeless. And yet the price to be paid for this achievement cannot be ignored for long. Taking the *social context* of this development into account, four implications emerge, all possibly involving limits to individual autonomy.

(1) The burden of knowledge. Within the medical context knowledge is seldom sought for its own sake, but for the sake of the therapeutic options it could provide. This is due to the fact that the goal of medicine is people's health. This goal is (ideally) achieved through therapy; diagnoses are only prerequisites for a correct choice of therapy. In the field of molecular medicine this leads to a serious problem. Knowledge about the genetic (co-)causes of diseases may have increased dramatically in the recent past, and the ability to test for diseases genetically likewise; and yet the increase in therapeutic options has remained modest in comparison. The gulf between the diagnostic and therapeutic possibilities available has continually increased, and this is unlikely to change in the foreseeable future. In many cases where genetic testing is carried out and proves positive, the medical profession can offer no more than that positive result. Sometimes this information alone may be highly valued, and yet this will not be the norm. Although relatively little is known to date about the psychological consequences of being aware of genetic risks, this kind of information is bound to be experienced by most as a burden or even a disaster. A person informed at the age of 18 or 20 about an increased risk of contracting cancer at the age of 50 will live the interim period of three decades under a heavy burden. Under these circumstances, the oracle of Delphi's call for self-knowledge becomes an unreasonable demand; and the notion that expanding one's insight necessarily benefits the autonomous planning of one's life appears naive.

(2) Resurrection of medical priesthood. The only option often remaining in the case of an unfavorable diagnosis is alteration of one's life-plan and adaptation of one's lifestyle to the genetic risk in question. Assuming the persons affected do not sink into bouts of resignation or depression, they will thus attempt to prevent or at least delay the disease they have been predicted to contract. This course of action is not, of course, reprehensible; in some cases it may even be successful. And yet this development will lead to a change in the social role of medicine. Instead of the medical profession working predominantly as a 'repair shop' with a firmly outlined task, an institution will emerge which will also exercise extensive social control over the behavior of entire populations. This can be summed up in two points: (a) The clients of the medical profession will no longer comprise the sick alone, but also and increasingly the *prospectively* sick – i.e. the acutely healthy. (b) The medical profession's original task of providing diagnoses

and therapies for disease will increasingly include prevention, in the sense of influencing lifestyles. 21st century physicians will assume a role occupied in 'primitive' societies by shamans and dominant in the monastic medicine of the Middle Ages: the physician as a priest, holding the secrets to a healthy lifestyle and directing patients or clients towards the 'right' way of living.

A look at the social and political context of this development reveals that shamanism based on genetic diagnostics will not lead to a renaissance of the spiritual dimension of traditional medicine; that it will probably extend far beyond mere consultation and seriously limit individual autonomy. We may assume that medical direction of lifestyle will acquire such authority as a result of various social mechanisms that individuals will be left with no choice. These mechanisms could be direct state coercion, but also and especially economic mechanisms (e.g. exclusion from insurance cover when medical advice is not followed) or numerous forms of indirect social pressure (influence of the media, of the medical profession, etc.). The price for advanced genetic knowledge and its potential benefits will thus be the emergence of a system based on genetic monitoring and behavioral control, assuming the similarly shaped functions of tradition and religion.

(3) Genetic knowledge as a social weapon. One of the characteristics of knowledge is the fact that it is almost impossible to limit. It can be multiplied at will and at little cost, and it can be transported vast distances within a few seconds. In addition, it can be combined and recombined in many different ways (like DNA) and can assume totally new characteristics as a result of these recombinations. Containment of genetic knowledge will therefore be almost impossible. It will possess a "spontaneous" tendency to exceed the boundaries of the medical system and pervade society. The manifold problems surrounding data protection, frequently debated in connection with genetic diagnostics, originate here. They arise from the fact that the data obtained by a genetic diagnosis will often be of interest not only to the individual in question, but also to third parties. Employers, insurance companies and the State immediately spring to mind (Andrews *et al.,* 1994; Draper, 1991; Nelkin and Trancredi, 1989). It is obvious that the interests of these institutions do not always coincide with those of the individuals concerned. For insurance companies, for example, genetic analyses can be a means of parting from genetically burdened persons, thus reducing risks – and costs. Cases such as these have already occurred. It thus seems reasonable to fear that genetic knowledge could become an instrument for discriminating against and disadvantaging persons who – through no fault of their own – are already disadvantaged by their genes. Moreover, this could also hinder or destroy the medical benefits of the technology: members of families with a high risk of contracting certain diseases may refuse to undergo genetic analyses

because they are afraid of subsequently being unable to take out health insurance.

(4) The dialectics of individualization. One of the great attractions of genetic diagnostics is its ability to attribute a particular risk to a particular individual. The resulting opportunities for preventive measures are obvious: a person who is aware of his or her own personal risk is quite likely to adapt his or her lifestyle or take other precautions in order to prevent the onset of the disease. What used to be an unknown and unalterable "fate" can, in the future, increasingly be influenced. In many cases we will thus be able to prevent or reduce suffering. The reverse side of this coin is, of course, that people who know their genetic "fate" and are able to influence it, will suddenly find themselves faced with a previously non-existent responsibility. A cancer or heart attack sufferer will now be forced to hear (from himself or others) that it was all his own fault: a diagnosis was not carried out in time, and no preventive measures were taken. Considering the current financial crisis within the public health care system, it is very improbable that such an attribution of responsibility will remain without social consequences. It will be tempting to laden upon those guilty of omitting to take preventive measures the resulting financial burdens too. Bearing this in mind, further desolidarization is to be feared in countries with public health insurance systems, of which there are many in Europe.

II. From Therapy to Construction

Of course, the expectations raised by gene technology regarding a 'molecular medicine' for the future not only include diagnostics, but also extend to therapy: gene technology will enable diseases not only to be better detected, but also – and especially – to be better treated (OTA, 1984). In this respect, however, little more than hopes or expectations have been realized so far. To date, the most important therapeutic innovations attributed to gene technology have all had to do with the production of medication (human insulin, growth hormones or blood coagulation factors). The long awaited breakthrough involving a *direct* application of gene technological methods to human beings in order to heal disease is still wanting.

Direct application is an idea dating right back to the beginnings of gene technology (Anderson, 1972). It consists of substituting missing or dysfunctional genes in human cells by introducing intact genes from the outside, thus stabilizing, improving or healing the patient's diseased state. Although the first offically authorized gene therapy experiment in 1990 is now a decade old, and although the transfer of genes to human somatic cells should easily have become routine by now judging by the optimistic prognoses around at the time, effective

gene therapeutic procedures are still not available. Once the present technical difficulties have been overcome, the great hope is to find not only alternative therapies for diseases already treatable today, but also and especially therapies for (genetic and non-genetic) diseases which are largely untreatable today (Nichols, 1988). Throughout the history of medicine, no other therapeutic procedure has been so intensively discussed before its test phase or so intensively controlled during its entire developmental phase. Somatic gene therapy may therefore be viewed as a model example of bioethically regulated technical innovation (Bayertz *et al.*, 1994). Although it has definitely had its fair share of (technical and ethical) problems and controversies (Anderson and Fletcher, 1980), it is nevertheless internationally believed to represent a desirable addition to previous medical options and one which does not raise any fundamentally new ethical issues (Walters, 1991; Walters and Palmer, 1997).

From its outset, the development of gene technology was surrounded by expectation, discussion and speculation about technical options exceeding far beyond the therapy of individual diseases in individual human beings and the ending of 'reproductive roulette' (Ramsey, 1970; Fletcher, 1974). Why restrict oneself to classical 'conservative' medicine when at some stage gene technology could provide an 'innovative' potential to improve mankind? Eugenic tradition, dating back to Ancient times, suddenly found a new technical ally in gene technology (Duster, 1990). Previously orientated towards the breeding paradigm, eugenics at last seemed capable of breaking through the technical, political and ethical boundaries inherent to it: variation and selection could be renounced in favor of a specific biological engineering of our descendants. To tide us over until the time when a direct controlling of the human gene pool would become possible, technologies such as selective interventions in the germ line, the cloning of human beings or the creation of human-animal hybrids seemingly presented themselves, all of which would allow at least a partial designing of our descendants in the meantime (Humber and Almeder, 1998; Pence, 1998a,b). Thus – so many hoped and at least as many feared – modern biotechnology was well on the way to facilitating the construction of individual human beings and ultimately the reconstruction of the entire human species.

Of course, only a handful have allowed their imaginations to run as far as a complete reconstruction of the human species. And yet it cannot be overlooked that, from its very start, the development of gene technology was linked to the prospect of a new technical and constructive relationship of the human race to itself. This has been emphasized not only by the advocates of gene technology, but also – and maybe even more so – by its critics (cf. Hubbard and Wald, 1993; Nelkin and Lindee, 1995). In all possibility, one group could be just as wrong as the other. Edward O. Wilson (1998, p. 277), for example, is keen to calm anxious

souls with his prophecy that future generations will be "genetically conservative," and that the development will never go so far as to apply genetic techniques excessively. This may or may not be true. And yet the crucial issue philosophically speaking is the *evaluation* of this constructive point of view. This is precisely where the ethical controversies are concentrated. Whereas the therapy of disease with the aid of gene technological methods is largely non-controversial, no consensus at all exists about constructive access (however far that may actually go) to the human race to itself. This initially means that it is not the application of gene technology to human beings *per se* which is in need of debate, but the question of which applications are morally permissible and which not. In other words, we have to decide where to draw the line (Anderson, 1989).

A. Where to draw the line?

A line needs to be drawn if, on the one hand, the potential of gene technology is to be exploited for medical (therapeutic) ends and yet, on the other hand, a transition to the 'construction' of human beings is to be avoided. In the discussion two main proposals have been made for drawing such a line:

(1) Somatic cells vs. germline. The abovementioned international consensus about the moral harmlessness of gene therapy refers to gene transfer in human somatic cells. This should be distinguished from gene transfer in germline cells, the difference being that, in the latter case, not only a particular organ of a particular individual is affected by the modification, but all cells plus those of descendants. Manipulations of the human germline have been debated repeatedly and, as a result of the unexpected difficulties encountered by somatic gene therapy, have become the subject of particularly emphatic debate over the last few years. Technical and ethical reservations about this strategy are very strong worldwide, however (Mauron and Thevoz, 1991). In some European countries (including Germany and Switzerland), germline interventions are even illegal, and Article 13 of the European *Convention on Human Rights and Biomedicine* (1997) says:

> An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purpose and only if its aim is not to introduce any modification in the genome of any descendants.

There are three - closely connected - reasons for drawing the line between somatic cell therapy (as permitted) and germline cell therapy (as non-permitted). (a) This is not an arbitrary borderline but a biologically given, real difference for

which there is empirical confirmation. The biological function of the human genome as a blueprint for the entire organism obviously differs from the genes located in the individual cells which are not totipotent. (b) Whereas gene transfer in somatic cells implies no more than manipulation of a single organ, the scope of germline interventions is far greater: they ultimately change the whole person. (c) And since the latter also affect all descendants of the manipulated individual, their supraindividual effect is potentially infinite.

Ignoring for a moment this totally justified reference to the incomparably grave consequences of intervening in the human germline, and sufficing it to say at this stage that the safety of this procedure would have to meet very high safety standards, this first proposal is convincing only if we assume an identity of genome and person, or at least a very close relationship between the two. And yet genetic determinism of this kind is hardly viable. Although biological relationships of course exist between genome and person, it is at least debatable whether these relationships are as close as the argument presupposes. Just the fact that identical twins possess the same genome and yet are obviously different *people* should be a warning. Neither is it safe to presume that all parts of the human genome are equally relevant to the personality. (After all, only 1% of human DNA basepairs are different from chimpanzee basepairs, rendering 99% identical). A fundamental axiological special position of the human germline is thus hardly plausible.

(2) Therapy vs. enhancement: Other bioethicists have proposed that the line between the permissible and the non-permissible be drawn not on the basis of biological and technical criteria, but with a view to the *goals* aimed at by each intervention. Regardless of whether an intervention were in somatic or germline cells, as long as it were aimed at the therapy or prevention of disease it would be ethically permissible. If it were directed at the enhancement of desirable characteristics, however, then it would be non-permissible (Anderson, 1989). This proposal pays tribute to health as representing a high and generally acknowledged value. The social institution of medicine heeds this value, and it would seem unreasonable to do without relevant technical operations altogether (cf. Harris, 1992; Parens, 1998).

At present it is difficult to imagine realistic indications for therapeutic or preventive interventions in the germline without any possible alternatives. With nearly all genetic diseases there is at least a 50% chance that an embryo will be generated without the diseased gene. With the aid of preimplantation diagnostics, as well as prenatal diagnostics and selective abortion, nearly all genetic defects are avoidable. And yet even if we presuppose the discovery of a therapeutic use for germline interventions which is not only reasonable but also necessary, this approach still poses serious problems. In particular, the division between therapeutic or preventive interventions on the one hand, and enhancement on the

other, is far less clear than it may appear at first sight. If we suppose, for example, that a person P has an above average genetic risk of contracting a particular serious disease, and if this risk were to be removed or normalized by means of genetic intervention (whether in somatic or germline cells), then this would clearly constitute prevention. We are aware, however, that (nearly) every human being has an above average risk of contracting several serious diseases. If several or maybe even all of these dispositions were to be eliminated in P, then this would be an obvious case of 'enhancement' or 'eugenics'. But if no clear division exists between prevention and 'enhancement', then this second proposal – based precisely on such a distinction – is only feasible if an arbitrary borderline is accepted.

B. Why draw a line?

The abovementioned difficulties surrounding the drawing of a line are more of a practical than a fundamental nature. In many other areas lacking clear borders we also draw ethical lines. We accept their partially arbitrary character because we are convinced that there have to be such lines. Maybe, instead of debating where to draw the line, we should be asking ourselves why one needs to be drawn at all. The discussion is dominated by four possible answers to this question of 'why'.

(1) Risk and prudence. The most obvious argument for drawing an ethical line between different types of genetic intervention stems from their different levels of immanent risk. We have already seen that germline interventions would have farther-reaching consequences than somatic cell interventions. And clearly the risks connected with the idea of 'enhancing' the human race are completely inestimable. In the foreseeable future the bold ideas of some authors regarding a reformation of human nature will have to remain fantastic:

> Compared with our present-day knowledge of the molecular biology of higher organisms, and our ignorance of the genetics of much of the normal variation in humans, many of these proposals are somewhat analogous to the idea that a boy who has just been given his first electronic set for Christmas, could successfully improve on the latest generation of computers (Vogel and Motulsky, 1996, p. 741).

At each stage in any technical development it is morally imperative to observe justification limits in the light of our ever-limited technical possibilities. In addition, not everything which is technically possible is also in the interests of those involved. Since this insight is often slow in coming, caution and reticence are even more advisable.

Such shrewd considerations do not, however, offer any obvious justification for a fixed and impassable line. It would no doubt be naive to presume that

technical limitations will one day disappear *altogether*, and yet it seems safe to predict that they will continue to be pushed and that our possibilities will continue to grow. Shrewd considerations will therefore (very importantly) protect us from hasty steps, but they will not be able to prevent completely the transition to human construction.

(2) The essence of the medical enterprise. Whilst the task of the social institution 'medicine' is to make sick people healthy again or, where this is impossible, to offer them relief in their diseased state, the 'enhancement' of human beings is a different matter altogether. Perceiving a human being as an object in need of perfection ceases to be a medical point of view and becomes a bioengineering project.

This second argument revolves around a generalization of what the medical institution has always believed itself to be – a belief already out of touch with reality. In some of its areas at least, medicine has long been developing in a direction tangibly linked to the idea of human autoevolution using gene technological means. Esthetic surgery (cf. Gilman, 1999), sports medicine and lifestyle drugs are all examples of the departure of medicine, at least partially, from the mere repair of health defects towards a service institution orientated towards the wishes of its customers. Of course this trend may be criticized as negative; many influential authors have done so. For the sociologist Talcott Parsons, esthetic surgical patients are not really patients at all (and this is why many insurance companies refuse to cover them). Leon Kass (1981) is another for whom cosmetic operations do not, strictly speaking, count as 'medical' operations: medicine's only inherent task is to remove physical defects and physically rooted discomfort.

This essentialist concept of medicine overlooks two points. Firstly, it is very difficult to render plausible why the goal of medicine cannot be extended beyond 'health' to include other values. 'Quality of life' could be one such value, especially considering its close connections with the classic value 'health'. Medicine would then emerge as an evolving institution, gradually exceeding its traditional base values and increasingly concerning itself with the fulfilment of all kinds of (morally sound) patient wishes. For H.T. Engelhardt, Jr. (1982), the goals of medical treatment are determined by individuals or groups and cannot be laid down in general terms. Secondly, this essentialist concept overlooks the fact that the term 'health' already contains an uneliminable reference to (extramedical) values, as well as to the relevant (sociohistorical) context. This reference means that constant change within the institution 'medicine' is preprogrammed. In a liberal society granting great scope for the free decisions of individuals, medicine would only be able to distance itself from this individualization trend if it were to adhere to a naturalist definition of 'health', detaching it from the factual wishes and changeable needs of individuals and attaching it to a normatively binding concept

of 'human nature'.

(3) The normativity of human nature. This brings us to probably the most fundamental philosophical objection of all regarding the idea of a gene technological reconstruction of the human race. According to this objection, human nature may not be viewed simply as 'biological matter' of neutral worth, which can be modified or optimized at will. Far more, human nature must be seen as an essential part of the human being, necessarily imposing normatively binding limitations. This position may be termed 'substantialist' (Bayertz, 1994) since it presupposes a fixed human substance and rejects as immoral all projects or actions which directly or indirectly call this substance into question. It is of secondary significance whether this substance and its binding nature are justified religiously (e.g. by appealing to God the Creator, the integrity of whose creations are to be respected by man) or with metaphysical and/or natural right arguments (e.g. by appealing to the dignity which human beings have by nature). Even Edward O. Wilson's prophecy that the human beings of the future will be "genetically conservative" is more than a mere (empirical) prediction. Its evocation of human nature causes it to assume an – albeit cloaked – normative dimension.

> Other than the repair of disabling defects, they will resist hereditary change. They will do so in order to save the emotions and epigenetic rules of mental development, because these elements compose the physical soul of the species. (Wilson, 1998, p. 277)

Even if it were possible to 'enhance' a person, according to Wilson that person would then cease to be human: "Neutralize the elements of human nature in favor of pure rationality, and the result would be badly constructed, protein-based computers." Human beings, so his message reads, cannot change themselves without losing themselves. Be it openly or cloaked, all of these positions postulate a categorical duty to preserve human nature or substance.

Any appeal to human nature is also riddled with difficulties. This begins with the fact that it remains – and presumably must remain – notoriously unclear what exactly 'human nature' is. If the legitimacy of technical manipulations in humans depends upon their non-violation of human 'nature' or substance', it becomes hugely significant to have a clear and unambiguous understanding of what exactly this 'nature' is or what exactly constitutes this 'substance'. And yet in place of precise definitions only vague hints are to be found. As neither a clear line 'upwards' nor 'downwards' can be detected, a coincidence seems unlikely. The plasticity and historicity of the human being hinder a clear 'upwards' division between 'nature' and 'culture', whilst the 'downwards' division between human beings and the animal kingdom is being increasingly blurred as science continues to progress (remember, for example, the enormous genetic affinity between us and

chimpanzees). Even if a clear definition of human nature were to be found, however, this would not actually help very much: it would still be unclear whether this human nature imposes ethical limitations on human activity. Why should we declare contingent natural facts for non-violable *eo ipso* and deny the realization of any number of human wishes, goals and interests (many of them understandable and legitimate) as a result? In short, the substantialist attitude is wide open to the metaethical accusation of naturalistic fallacy.

(4) Playing God. One categorical objection often raised to any notion of genetic modification or 'improvement' of human beings is that it entails assuming privileges reserved for God. From a religious point of view, this objection seems reasonable since nearly all religions attribute the creation of the human race to gods or god-like beings. Apart from the fact that religious convictions do exist which (under certain circumstances) advocate genetically-based human self-manipulation (cf. Process Theology) or want to leave the door open for further reflection,[3] it is difficult to know where to draw the line with this argumentation. Since not *every* intervention in human nature may be rejected, since we attempt to improve our (phenotypical) nature legitimately in several respects, and since we ultimately influence – albeit relatively non-specifically – the genes of our descendants, criteria must be established to differentiate which interventions are to be deemed illegitimate. In addition, religious faith cannot be taken as an underlying structure of generally binding norms in a pluralistic society. It is possible, however, to shed a very secular light on the "playing God" argument.

> When the objection of playing God is separated from the idea that intervening in this aspect of the natural world is a kind of blasphemy, it is a protest against a particular group of people, necessarily fallible and limited, taking decisions so important to our future. This protest may be on grounds of the bad consequences, such as loss of variety of people, that would come from the imaginative limits of those taking the decisions. Or it may be an expresssion of opposition to such concentration of power, perhaps with the thought: “What right have *they* to decide what kinds of people there should be?” (Glover, 1984, p. 47)

Insofar as this argument draws attention to lacking human wisdom and the fallibility of human decisions, it can only be agreed with. But it certainly does not justify a categorical "No!" to all kinds of intervention in the genetic makeup of human beings; what it justifies is merely a categorical imperative to be extremely cautious in the course of any such undertaking. What carries more weight in this argument is its reference to the power of the manipulators. Even if it were possible to avoid or limit the dangers of a concentration of gene power through a strict individualization of decisions, the decentral power of many individual decision makers would become a new kind of power of (present) human beings over (future) human beings, undermining the autonomy of the latter.

C. Freedom to self-manipulate (subjectivism)

Bearing these considerations in mind, the application of gene technology does not seem bound by any given or fixed moral limitations. This result will please those who believe the specifically human not to be human 'nature', but the ability of human beings to design their lives and world actively and consciously. According to this line of thinking, human beings are different from all other creatures through their free relationship to both the surrounding nature and their own nature, both of which they can change to suit their needs. This position may be termed 'subjectivist' (Bayertz, 1994) because human beings regard themselves primarily as subjects, not bound by nature in their thinking and actions but capable of choosing freely and shaping their world as they see fit. It should be stressed that for subjectivists this is not just a description of the *conditio humana*, but an *evaluative* analysis of the human essence. The subjectivity of the human being is not merely factual but morally decisive: everything in this world with any value at all has that value through human beings and for human beings. Accordingly, nature is 'of neutral worth'; it is 'material' for the human desire to shape things, but it does not possess any value in its own right. This is also true of the human body. It also belongs to this 'outside world' which can be reshaped at will. Nature can and should be 'dominated' for the purpose of self-manipulation and self-realization, both in the human body and in any other parts of nature.

Subjectivism first evolved completely independently of any references to biotechnology or gene technology. It has been the concern of numerous philosophers, especially in the New Age, including – in a particularly extreme form – Jean-Paul Sartre. In his philosophical terminology, human beings 'design' and 'project' themselves, a very literal vocabulary when applied to human plans for genetic self-alteration. The following passage by Sartre comes across as infinite autoevolution devoid of goals, translated into the language of 'phenomenological ontology':

> Since freedom is a being-without-support and without-a-springboard, the project in order to be must be constantly renewed. I choose myself perpetually and can never be merely by virtue of having-been-chosen; otherwise I should fall into the pure and simple existence of the in-itself (...) Our particular projects, aimed at the realization in the world of a particular end, are united in the global project which we are. But precisely because we are wholly choice and act, these partial projects are not determined by the global project. They must themselves be choices; and a certain margin of contingency, of unpredictability, and of the absurd is allowed to each of them, although each project as it is projected is the specification of the global project on the occasion of particular elements in the situation and so is always understood in relation to the totality of my being-in-the-world. (Sartre, 1958, pp. 480f.)

According to Sartre, human free self-design is independent of genetic self-alteration. Human beings have always, and in all circumstances, designed themselves. The fact that human beings had already begun to intervene in the process of reproduction back in primitive societies, whether for contraceptive or for 'proceptive' purposes, is an indication of a continuity of wishes and goals reaching into the present day. Yet if we take a look at the limited and incomplete means available then, and compare them with those possibly available in the future, then it becomes clear how little continuity there is as far as technological means are concerned. The new quality which gene and reproduction technology has lent to human self-determination primarily consists in its technological character, which renders human nature accessible to change and design for subjective purposes in previously unthinkable proportions. Gene technology appears as a huge extension to and reinforcement of subjectivity as far as the biological foundation of human existence is concerned.

There can hardly be any doubt that subjectivism is the currently dominant position in the philosophical evaluation of gene technology. Although in the recent past theoretical efforts to revalidate nature in general (in the context of environmental ethics) and human nature in particular have intensified, and although this expressly happens for the purpose of preventing human subjectivity from going too far, the growing options available to human beings and the consequent ever-growing scope for design of the world and self are generally evaluated positively, even by most bioethicists. Admittedly most of them stop short of Sartre's concept of total freedom; and yet few are prepared to acknowledge categorical limitations to human activity based solely on human nature. The achievements of reproduction technology enable "free individuals to achieve the biological destinies they choose, as, for example, within the area of reproduction" (Engelhardt, 1982, p.72). Why should we refrain from redesigning the world and ourselves in line with our wishes and interests if biotechnology could make it all possible? The corollary of this is: If human beings are autonomous, the moral legitimacy of technological intervention in reproduction may no longer be disputed *a priori*, not even the most fantastic measures within a strategy of genetically improving the human race could be excluded for metaphysical reasons. (This is diametrically opposed to the substantialist standpoint.)

And yet what at first sight may look like a triumph for autonomy, proves at second glance to be a problem of some intricacy. What is increased by the achievements of biotechnology and gene technology is the autonomy of the living, but not that of the future human beings to be 'enhanced' using the new procedures. At least at two levels this leads to limitations which are far graver than they may seem initially.

(1) Risks for others: At all times and in all places, technological activity involves risks. This is also true of biotechnology and gene technology in the future. Matters of risk are usually interpreted as matters of wisdom, and yet that is not the case here. The fundamentally unavoidable risks entered into within a human 'enhancement' project acquire the status of an ethical problem because it is not us entering into them: we burden *other,* future people with them instead. Since these people are not capable of giving their consent, this can only be deemed an ethically permissible course (at a stretch) if the risks are in an appropriate ratio to the expected benefits of the modification for the individuals involved. This would seldom be the case.

(2) Goals for others. This brings us to the goals which enhancement could possibly have. 'Enhancement' is an evaluative term. The further our technical options extend, the more debatable the goals of such modifications become. Two possibilities arise in this context. The first consists in orientating the modifications towards a generally binding ideal or the interests of society. This was the position of classical eugenics. This would obviously increase the power of society over individuals enormously and safeguard it biologically. Far more appropriate in a liberal society is the granting of as much scope as possible for decisions and actions and the promotion of individual multiplicity. In this light, the second possibility seems preferable: to allow parents to decide the goals behind gene technological changes to their offspring. However promising this idea may appear, it would be naive to ignore how tied individuals really are in their decision-making. *De facto* most of them would not reach their decisions autonomously but on the basis of numerous social influences. Precisely because the decisions parents would be making would be important, they would seek orientation from the media, the sports world and relevant 'experts'; analogous to the naming of children[4] and the booms of particular methods of upbringing, fashions and semi-scientific ideologies would play an important role.

The problems facing both of the above options are further aggravated by the temporal distance between the begetters and the begotten: the constructors would opt for those values highly regarded in their *current* social context and try to steer their offspring towards *these* values. And yet what is regarded as positive today will not necessarily be so in our offspring's tomorrow. We never know what characteristics are going to be called for in the future. Just as the science-fictional future usually turns out to be no more than an extrapolation of the present, the 'future human being' will be seen as the current human being with all of its positive characteristics increased. Autonomously speaking this means: the price to be paid for the constructive potential of gene technology is the autonomy of those it would affect. This is markedly different from cosmetic surgery or doping, where the

individuals opting for them wish to profit from them themselves and will bear the consequences for doing so during their own lifetimes.

III. ETHICS AND GENETHICS

We pointed out early on that some of the issues raised by GenEthics are very fundamental: 'fundamental' not only in the sense that they deeply affect the future of the human race, but also in the sense that it is difficult to express them in the vocabulary of established ethics, that they even seem to exceed the scope of conventional ethics altogether. Since it has not been possible within the framework of this paper to examine these issues in any depth, we would at least like to conclude with a reference to them, in the hope that they may be paid more attention in the future. This should be the case, at least as long as "bioethics" is interpreted not only as an undertaking which attempts to solve more or less pragmatically the most urgent issues on the agenda at any given time, but also as a genuinely *philosophical* undertaking, going beyond the practical problems of the day in order to examine fundamental metaethical and metaphysical questions as well.

The *first* of these issues stems from the fact that gene technology has (not only, but also) to do with unborn human beings. The bold visions of genetic modification, whether of single individuals or the entire human race, concern the members of future generations. There is a theory that ethical principles developed for actual people cannot just automatically be applied to possible people, and there are arguments to support this. Any attempt to extend the validity of these principles to include possible people seems to lead to paradoxes which in turn signify the end of any meaningful ethical discourse. Unlike other liberal and humanistic expansions of the reference group of these principles (to women, other races, animals)

> sensitivity to the lot of future people cannot be expressed simply by embracing 'them' into the moral community. For it is exactly the indeterminacy of 'them' which makes it impossible to apply contractarian, Kantian, or utilitarian principles to decide 'their' lot. It is not the assumption of timelessness of the moral community which makes theories of ethics incapable of handling genesis problems, but rather the paradox of being expected to provide ethical principles for membership in the community which is the basis of all ethical principles. (Heyd, 1992, pp. 63f.)

If this analysis is correct, we encounter problems here which lie beyond the grip of ethical judgement; we have reached a limit of ethical theory.

Secondly, one of the exceptional qualities of gene technology is its 'synthetic' or 'constructive' potential. At least in principle and in the long-term, it will enable

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the human genome to be accessed specifically and deliberately. The prospect of a medicine which no longer merely 'repairs' human beings, but also alters and 'improves' them calls into question the moral status of *human nature*. Is it little more than organic matter at stake here, or should an inherent value be attributed to it? Modern ethics has abolished the idea of human nature – and likewise (external) Nature – possessing an inherent value. Accordingly, moral evaluations are to refer exclusively to human wishes, needs or interests. Independently of these instances, Nature herself, or any of her individual states can be neither the source nor the object of such an evaluation. This position, at least with regard to Nature, has been called into question in the light of the ecological crisis (cf. Krebs, 1999). And it is also being increasingly called into question with regard to human nature. This revalidation of human nature can be asserted with 'strong' normative claims or in a moderate sense, comprehending its normativity more in a recommending sense (Siep, 1996). One of the main arguments of the moderate position is the theory that genuine human flourishing may not only be described in subjective termini, but also has an objective and natural dimension which presupposes the recognition of a graduated intrinsic value of Nature (including human nature).

It seems obvious that both of these issues are very fundamental, and that not only our ethical judgment regarding this or that gene technological option depends upon their being answered, but also the structure and content of our ethical thinking altogether. This may be seen as an indication that technological progress not only forces us to assume responsibility for options which continue to extend further and deeper, but also for the ethical categories and principles with which we evaluate these options. This *metaresponsibility* (Bayertz, 1994, pp.181-197) is by no means the smallest problem currently confronting the realm of ethics. Once we begin shaping human nature, we shall also be forced to shape the ethical principles which allow or forbid just this.

Department of Philosophy
University of Münster, Germany

Center for Medical Ethics at the Markus-Hospital
Frankfurt/M., Germany

NOTES

1. Translated by Sarah L. Kirkby (B.A. Hons.)

2. There is no room here to go into detail about the scientific and considerable economic interests involved in uncovering the genetic foundations of ethnic variation. Lucrative diagnostic and therapeutic agents can be developed on the basis of single genes (this is incidentally also true at an individual level).

3. Within "the scope of a theology of creation that emphasizes God's ongoing creative work and that pictures the human being as the created co-creator" the door "to the issue of germ-line intervention for the purpose of therapy and even for enhancing the quality of human life (...) must be kept open" (Peters, 1995, p. 379).

4. Just as social and political trends influence the choice of first names (cf. Wolffssohn and Brechenmacher, 1999).

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Edited by

GEORGE KHUSHF

Center for Bioethics and Medical Humanities and
Department of Philosophy,
University of South Carolina, Columbia, SC, U.S.A.

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