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# Future man - No future man

Connecting the technological, cultural  
and political dots of human enhancement

Rinie van Est, Pim Klaassen,  
Mirjam Schuijff and Martijntje Smits

June 2008 - The Hague - Rathenau Institute





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## Executive Summary

In the last decades, the development of technologies previously thought to be science fiction has sparked a new idea: humans could take their evolution into their own hands, that is, all kinds of human traits could be aided by technological developments. This enhanced human being, or Homo sapiens 2.0, is seen both as a dream and nightmare in the making. A central theme within the current debate concerns the tricky distinction between treatment and enhancement. This essay reviews human enhancement from a cultural, political and technological perspective, in order to draw up an initial agenda for research and public debate on human enhancement.

We define human enhancement as "the use of biomedical technology to achieve goals other than the treatment or prevention of disease" (see chapter two). Existing enhancement technologies, like dietary supplements and hearing aids, are relatively uncontroversial. Other examples prompt more public discussion: cosmetic surgery, the use of drugs beyond their original medical settings, narcotics and doping in sports. These technologies in combination with prospected future enhancement technologies spur public debate on human enhancement. Examples are the genetic engineering of the human body, or even the human embryo. In particular, the convergence of nano-, bio-, and information technologies and the cognitive sciences (NBIC) give rise to many bold visions, like the future possibility to upload brains into a computer.

In chapter three, the human enhancement debate is traced back to the early enlightenment period. Later, in the late 19th and early 20th century, evolutionary theory as developed by Darwin and Mendel led to the idea and practice of eugenics. A so-called authoritarian eugenics developed, in which states took the responsibility to improve the genetic quality of the state. The terrible downside of this form of eugenics was proven by the horrific consequences of nazi-eugenics.

After the Second World War the rise of modern life sciences really took off. The scientific endeavour more and more focused on mastering human life itself. In the wake of this development, a loose movement of so-called transhumanists developed in the 1970s. Transhumanists advocate the individual right to gain control over your life and improve your mental and physical capacities. The human enhancement debate is not a simple revival of the eugenics debate. Besides genetics, IT, nanotechnology and cognitive sciences play a role. More important, it is fueled by the belief that individual free choice should determine what constitutes human enhancement. Therefore the term liberal bio-politics is used to refer to the liberal political climate in which modern bio-politics is being developed.

To illustrate the way how the new liberal bio-politics is developing in various social contexts four cases are described in chapter four: the drug Ritalin, Deep Brain Stimulation, gene therapy and gene doping, and pre-implantation genetic diagnosis. The cases reveal ample social debate and regulation. However, regulation develops slowly, following the development of the technologies. Regulations, furthermore, focus on protecting the individual from harm and on setting moral boundaries. Several questions deserve a prominent place on the public and research agenda of our society. We recommend the following five broad themes and questions as relevant areas for further research and public debate on human enhancement:

1. Science, technology and fiction for human enhancement  
What visions, fantasies and expectations are expressed by scientists and engineers of human enhancement technologies? How real are the dreams expressed in science fiction and how do they drive actual developments? If the wild fantasies are separated from realistic expectations, then the questions of legitimacy and the ethical aspects of the research become realistic as well and can be addressed. For example, when science for treatment leads to human enhancement technologies, can such research still be legitimized from the perspective of therapy and if not, how to conduct such research in an ethically sound way?
2. Human enhancement practices  
How to regulate human enhancement in a variety of social practices by a diverse group of actors? Current enhancement practices have regulations, but they are constantly challenged and have regulatory wastelands. That is: the technology is also used in ways not covered by the regulation. Such usage might give rise to new emancipatory movements, but also criminal practices. Therefore, it is important to study and discuss the (non-)regulation and usage of human enhancement technologies.
3. The shaping of the self  
What is the meaning of enhancement technologies for shaping and perceiving ourselves? Self-fulfilment is a major value in our culture, and human enhancement technologies can be used for this in ways unseen before. But how will this impact, for example, the way we see ourselves?
4. Images of the future  
By which socio-technical scenarios can we picture possible ways in which human enhancement and society develop? Current regulation does not pay enough attention to the long-term impacts of the technological developments. Scenarios are helpful in assessing the long-term impacts of the technologies and in stimulating future reflection and policymaking.
5. Do the dots of human enhancement connect to a wave?  
What is the political dimension of human enhancement? Does the upcoming debate on human enhancement present a new bio-political dimension and does this dimension challenge mankind in ways similar to the ecological crisis?

## 1. Introduction

This century started ominously. On the seventh day – our information society just took a rest after the shock of the millennium bug, which had not occurred – one of the world's most influential futurists, Alvin Toffler (January 7, 2000), made a very provocative statement in *USA Today*:

- The biggest question facing the 21<sup>st</sup> century can be stated in a few words: What does it mean to be “human?” The answer to that question will affect our most basic values and moral codes. And it may lead to an intensification of religious and moral conflict across the planet. ●●

In particular, Toffler argues, it is the next phase of the information revolution – the fusion of the digital revolution with the genetic and biological revolution – which will force mankind to reconsider what we mean by “human”. In common language the words “being human” generally implicate the contradictory and ever changing mix of moods and emotions: being passionate, indifferent, lazy, fallible, weak and strong, proud, jealous, ambitious, playful, compassionate, cruel, and above all fragile. From an evolutionary perspective, a human being is a specific type of animal: *Homo Sapiens Sapiens*; an intelligent creature *supposedly* guided by values and norms. Charles Darwin showed that human beings are related via genealogical trees to the apes. Since evolution never stops, Darwinism also opened up a future prospect on being human: in generations from now a different type of ‘post-human’ species may develop.

During the last decade a growing circle of writers, philosophers, historians, politicians, and technologists has started to conceive mankind as outdated or at least threatened. It seems that the Darwinian lesson starts to sink in that *Homo Sapiens Sapiens* is merely one evolutionary phase on an indefinite path, coming from a highly contingent past and moving into a wholly uncertain future. The expectation is that this *Mängelwesen* will be faced – within this century – with competition from a new type of species: *Homo Sapiens 2.0*. Technology will enable this ‘new and improved’ version of man. In the form of human clones, the bionic woman, the six-million dollar man, intelligent humanoid robots and genetic mutant superheroes, prototypes already float around in popular culture for some time. According to many, science today is rapidly turning science fiction into history, since the speed of technological and scientific progress is giving these creatures scientific credibility. Parallel to this growing belief in and speculation on science and technology's potential for moving mankind on a purportedly higher plane, the number of critical reflections on mankind's projected future has been steadily growing over the last years. This debate is being held under the umbrella term “human enhancement”.



To name only some landmarks in this upcoming discourse: K. Eric Drexler (1986) *Engines of creation: The coming era of nanotechnology*; Gregory Stock's (1993) *Metaman: The merging of humans and machines*; Lee Silver's (1998) *Remaking Eden: Cloning and beyond in a Brave New World*; Erik Parens' (1998) *Enhancing human traits: Ethical and social implications*; Peter Sloterdijk's (1999) *Regeln für den Menschenpark*; Bill Joy's (2000) pamphlet *Why the future doesn't need us*; the American National Science Foundation's (NSF) *Converging technologies for improving human performance* (Roco and Bainbridge 2002), Francis Fukuyama's (2002) *Our posthuman future*, Bill McKibben's (2003) *Enough: Staying human in an engineered age*; Jürgen Habermas' (2003) *The Future of Human Nature*, the Rathenau Institute's technology festival *Homo Sapiens 2.0 Festival over de maakbare mens* (2003), James Hughes' *Citizen Cyborg* (2004); the establishment of the Flemish organisation *Maakbare Mens* by a.o. Luc Desmedt in 2004; Michel Houellebecq's (2005) *La Possibilité d'une île*, the DEMOS publication *Better Humans? The politics of human enhancement and life extension* (Miller and Wilsdon 2006)

A central point of discussion revolves around the question what is meant with better humans. In other words: what is the purpose of enhancement technologies? Should *Homo Sapiens 2.0* walk faster, be smarter, be happier, be more sweet to his fellow 'cyborg citizens', be more obedient? Advocates of enhancement often relate 'better' to improving individualistic qualities that tend to lead to competitive and thus evolutionary advantage (cf. Wilson 2007). Preferred traits that research should focus on are intelligence, physical strength, beauty, freedom from disease and longevity. Opponents, like Langdon Winner (2003), rightly or wrongly, complain that "other qualities widely recognised as crucial to our well-being – empathy, cooperativeness, the capacity to love and nurture – are never mentioned on the agendas of post-humanist science".

Most ordinary people would probably frown their brows when hearing about the various statements above: should we really take this discussion about human enhancement seriously? In order to assess this question, we should get clear on what we actually mean with *human enhancement*. Only then can we value the current debate and consider whether it is typical for our era, whether it is part of a larger historical and cultural development, or whether it is just some highly localised and specialised hype among a small group of technophobes and technophiles. Moreover, only then can the political relevance of the idea of and practices connected to *human enhancement* be weighted and only then we can start to ask what the core issues are from a political perspective. What – if man's future is really at stake – should governments and the public do? This essay will give the reader some insights to value the (ir) relevance of these questions.

### Content, aim and approach

Our main objective is to provide an initial agenda for research and public discussion on human enhancement. To arrive at such an agenda some groundwork needs to be done. As the historian Bess (2008) argues: "Technologies of human enhancement are incrementally becoming a reality in today's society, but we don't connect the dots. ... What we miss, with this fragmentary perspective, is the importance of all these developments, taken together." This essay is a humble attempt to connect some of the technological, cultural, and political dots.





Section 2 loosely introduces the concept of human enhancement, by giving examples of current and future technologies that regularly play a role in or even drive the debate on human enhancement. We will investigate to what extent existing and future technologies spur different types of debates. Addressing this question will help us find some analytical guidelines for the remainder of the essay.

Section 3 tells the big story about human enhancement. It tries to position the current upcoming debate on human enhancement within a broader historical, cultural and technological context. Why is the awareness about human enhancement growing at this specific moment in time? This section describes some parts of the historical roots of today's human enhancement debate.

Section 4 contains four case studies about current and future 'enhancement' technologies. A first case stems from pharmacology. It is about the use of the drug methylphenidate, better known by its commercial name Ritalin, to promote concentration. The second case concerns brain implants, and thus is about brain-machine interaction. The two other case studies stem from genetics: gene doping and designer babies. By means of this bottom-up approach we try to acknowledge the incremental and often chaotic manner in which technologies and policies commonly develop in specific social domains (cf. Van Est 1999).

Based on the groundwork done in the former two sections – the historical picture and four case studies –, the fifth and final section provides some elements for an agenda for research and public discussion on human enhancement.

## 2. Examples of human enhancement technologies

The current discussion on human enhancement hinges on technology. Of course, there are many other ways to enhance human performance. Think of highly regarded non-technological ways of human enhancement, such as education, meditation and working out in the gym. Nevertheless, and rightly or wrongly, the current debate on human enhancement is primarily focused on technology. This is made explicit in Douglas's (2007) definition of human enhancement as "the use of biomedical technology to achieve goals, other than the treatment or prevention of disease". Significantly, this definition incorporates in human enhancement technological interventions in all kinds of non-medical domains, like sports, education, work, military, arts and entertainment. That *human enhancement* is such a broad notion will be further illustrated below.

This section will give the reader an impression of the sort of enhancement technologies that are around now and are expected in the future. It also gives a feel of the kind of discussions these existing and futuristic technologies spur. Some see a difference between existing everyday enhancement technologies and those that might alter the future generations in more fundamental ways (cf. Miller and Wilsdon 2006). This would hint at an historical twist in the type of technologies used for human enhancement and / or their aims and impacts. We will study to what extent existing and future technologies and the debates they trigger differ. Are the technologies and debates distinct or strongly linked? This orientation will also provide some analytical guidelines for the rest of the essay.

### 2.1. Everyday enhancement technologies

A wealth of enhancement technologies is already common for quite some time – think of dietary supplements to improve health and wellbeing, prosthetic limbs for the disabled, vaccination to increase immunity of disease, (reading) glasses, and hearing aids (Chan and Harris 2007). Except for vaccination, these examples meet with little debate. The same cannot be said of the following well-known categories of enhancement technologies, which spur more public discussion than those aforementioned technologies: cosmetic surgery, the use of drugs beyond their original medical setting, narcotics and doping in sports.

The cosmetic surgery industry has seen gigantic annual growth rates during the last decade (Aitkenhead 2006). Aesthetics is its booming market. This industry offers interventions into the human body ranging from Botox injections, breast implants, penis augmentation, to 'vaginal rejuvenation', and whitening the colour of one's skin. The growth of this industry reflects a radical change in public attitude towards these human enhancement technologies. As the journalist Aitkenhead (2006: 104) argues: "A practice widely regarded not a decade ago as physically risky, morally doubtful, prohibitively expensive and socially embarrassing has been re-branded as something so innocuous and sensible as to be mundane." According to her the media plays an important role in this cultural shift.

Ritalin, beta-blockers and Modafinil are all drugs which are developed and used in a regulated manner within the medical sector to treat various diseases. These drugs, however, are also used outside the medical domain. Methylphenidate (Ritalin) is used by normal students to enhance their concentration, beta-blockers are used by artists and scientists to calm their nerves before performance, and it is reported that American pilots in the recent war in Iraq routinely used Modafinil to enhance alertness and reduce need of sleep (Rose 2006).



Narcotics constitute a much publicly debated form of enhancement technologies, opinions about which range from 'legalise it' to promoting the 'war on drugs'. Their use is abundant in nightlife. Think of the vast amount of party people who boost their energy and endurance or change their 'mind style' through the use of Ecstasy or cannabis, or simply via smoking nicotine or drinking alcohol. The use of psychedelics by artists to increase their creativity or escape their misery is also (in) famous, with the addicted soul singer Amy Winehouse – who recently won five Grammy Awards as she was staying at a drug rehabilitation centre – as the latest popular example.

Doping in sports is another area in which human enhancement has become common practice and gets a lot of media attention (cf. Douglas 2007). Over the last year, the use of EPO in cycling and anabolic steroids within American baseball has been all over the news. The widespread use of doping in competitive sports has led to the creation of the World Anti-Doping Agency in 1999 and stricter anti-doping policies. Because the testing of new technologies in sports is often illegal and unsafe, the use of unproven enhancements in athletics is quite commonplace (King and Robeson 2007). Even worse, there are lots of enhancements that increase the likelihood or severity of injury to athletes, or even cause death (cf. Van Hilvoorde & Pasveer 2005).

### Coping with human nature and culture

In the introduction two characters were introduced: Homo Sapiens (the emotional, fallible and fragile creature as we experience ourselves and others in normal life to be) and Homo Sapiens 2.0 (a technologically improved version of today's man, ahead of us on the Darwinian timeline). On first sight the above described everyday enhancement technologies do not refer to this latter future image of man. The examples reveal longstanding debates around messy and complex political issues, like the role of drugs in society. Each of these cases is, taken in itself, all too human. They show the human struggle that our attempt at coping with the world constitutes in all kinds of ways, from escapism to striving for gold. Many reflections on such matters concern the contextual factors that drive these developments, like cultural changes, the role of capitalism, regulation and its implementation, *et cetera*.

Since these existing human enhancement technologies reveal such mundane issues, a relevant question becomes whether they can tell us something about the much heralded future of enhancing human traits. John Harris, the transhumanist author of *Wonderwoman and superman* (1992) and *Enhancing evolution* (2007), would probably say no. Recently he even explicitly dismissed cosmetic surgery and doping in sports as examples of enhancement technologies (Chan and Harris 2007). But other scholars do see the development and usage of existing technologies as very instructive when it comes to understanding our future. For example, Hoberman sees the current developments with regard to doping in sports as "a kind of very confused referendum about the future of human enhancement." (quoted in Garreau 2006: 5) Others believe that current examples can make us sensitive about the driving forces behind human enhancement technologies. For example, Gems (1999) fears that the current experience with cosmetic surgery might give a good indication of how other enhancement technologies will come to us in the future. In particular, the role of capitalism in creating new 'illnesses' is alarming, and should be given attention, according to Gems.

One might conclude that the debates on existing everyday enhancement technologies are about human nature, but also human culture. They point at the necessity of taking a *historical* and *contextual* approach when studying human enhancement. Similarly, thinking about *future* enhancement technologies can be argued to be just as important.

## 2.2. Futuristic enhancement technologies

A new set of enhancement possibilities is expected to open up within the next years. Gene doping – expected to be the next phase in the area of competitive sports and doping (cf. Van Hilvoorde & Pasveer 2005) – is only one example. Scientists have already created genetically modified “mighty mice”, which are extremely large and muscular. When will this technology be used in human athletes, if it isn’t already? Advances in nanotechnology, biotechnology, information technology and cognitive sciences (abbreviated as NBIC) deliver provoking prospects on human enhancement, from tissue engineering to ‘uploading’ our brains onto computers. The British think-tank Demos calls this ‘the radical end of the enhancement spectrum’. It proclaims: “Within the next 30 years, it may become commonplace to alter the genetic make-up of our children, to insert artificial implants into our bodies, or to radically extend life expectancy.” (Miller and Wilson 2006)

Gregory Stock (1993, 2002) has some clear ideas about such a future. He believes that humans will inevitably transcend their current biological make-up because of genetic engineering. Just like humans for long have taken control over the breeding of dogs, they will now take control over their own genetic evolution. According to Stock humans will become as physically and intellectually divergent as “poodles and Great Danes” (cf. Galton 1909). This will be done by germ-line engineering. Germ line interventions will change the genetic makeup of the human embryo at the very start. Stock believes that adding a new artificial chromosome pair to the embryo will be the safest way to substantially modify humans, and improve some mental or physical characteristics. “The auxiliary chromosome would be a universal delivery vehicle for gene modules fashioned by medical geneticists throughout the world.” (quoted in Garreau 2006: 115)

### Radically altering human nature

The radical technologies fuel the debate on the future of mankind, under the premise and promise that they will fundamentally alter human nature. Many of the moral concerns about future enhancement technologies revolve around the tricky distinction between treatments on the one hand and enhancement on the other. How this partly philosophical and partly pragmatic debate is resolved, will impact on what health care systems will and will not provide for. The distinction between ‘making people better’ and ‘making better people’ is seen as problematic for a number of reasons. One of the reasons is that illness can be culturally constructed – that is to say, that what is being categorised as illness varies historically as well as culturally (Foucault 1965). For example, in the West homosexual behaviour was widely regarded as symptom of the *illness of being gay* until very recently (cf. Shorter 1997). What is seen as normal – length, intelligence, concentration, sexual behaviour – can shift over time. Therefore, some authors claim – particularly transhumanists – that the distinction between treatment and enhancement is not useful, or even untenable (cf. Silver 1998; Chan and Harris 2007). Harris (2007) holds that the discussion should not focus on such a distinction, but on the question of whether a certain intervention offers benefits and minimising the risks involved.



Selgelid (2007) doesn't want to dismiss the treatment-enhancement distinction altogether, but he does want to amend it. According to him we should recognise that we face a continuous spectrum and that it only makes sense to speak about treatment and enhancement in terms of degree and prototypical cases. A person who has a high quality of life and uses an intervention to additionally improve her quality of life is a prototypical case at the enhancement side of the spectrum. To illustrate his point, Selgelid presents the following example of human enhancement:

- "Suppose that prenatal genetic testing reveals that our foetus will be normal and healthy – but that researchers offer the opportunity to try an experimental genetic technique that sounds likely, based on previous evidence from animal experiments, to boost her IQ (Intelligent Quotient) by 25 percent." ●●

But even at the 'radical end of the enhancement spectrum' the distinction between treatment and enhancement is not as self-evident as it seems. It is hard to escape the question: what do we define as 'normal' – or perhaps even more urgently, *how* do we define what we conceive as normal? In defining the normal and the pathological, do (and *should*) we follow cultural norms (or prejudices), statistics, evolutionary survival value, personal preference, "the moral law within us", *et cetera*? Making this question more tangible, do we, for example, consider a baby with Down Syndrome as normal? If so, would we consider boosting up the IQ of a baby with Down Syndrome as treatment or as human enhancement? Given the complexity of such questions and the difficulty of resolving them once and for all, Selgelid concludes that it is not appropriate to talk about the ethics of treatment versus enhancement as though these were categorically different things. Instead: "It is more fruitful to talk about particular interventions – and examine the ethics of these on a case by case basis."

Fukuyama (2002) takes this argument one step further. He agrees with the theoretical view that it is hard to draw a clear line between treatment and enhancement. Nevertheless, he pleads to draw such a line from a practical and political point of view. Practice shows that this is constantly happening. The current use of the drug methylphenidate (Ritalin) by children with ADHD illustrates this (cf. Pieters et al. 2002). From a regulatory perspective the line is drawn between using Ritalin on medical prescription ('treatment') and the use of Ritalin by 'normal' people for the purpose of increasing concentration and alertness.

### 2.3 Connecting present and future technologies

At the beginning of this section we asked ourselves what kind of discussions the existing and future enhancement technologies would spur about human enhancement. Both discussions point to the importance of studying various interventions on a case by case basis. Moreover, we should try to avoid a narrow fixation on technological means. In particular with respect to futuristic technologies this is a dangerous pitfall. A broad outlook is necessary, which includes both an historical and socio-cultural perspective. This also opens up the possibility to consider the social meaning that certain human enhancement technologies are given in various social practices.

Such broad outlook provides also a manner to cope with the difference between existing and new radical enhancement technologies. Of course, it is impossible to foresee the full impact future technologies will have. Nevertheless, it is clear that future technologies will to all likelihood build on current ones. For example, a “radical” enhancement technology like germ line genetic modification hinges on the previously developed and implemented technology of in vitro fertilisation (IVF). This is not meant as a slippery slope argument. Rather, it is about being aware of the different phases in the development of technology and the systems character. The bottom-line is that talking about radical enhancement technologies includes talking about the historical and current debate on IVF. And vice versa; talking about IVF, should also involve the debate on genetically engineered babies, whether such a future option will ever be realised or not. Including future visions into the debate is also a way to address the longer-term social issues related to human enhancement.

The present discussion on human enhancement technologies, whether existing or futuristic, demands reflection that is going back into the past and forth into the future. This prevents a focus in the human enhancement debate on futuristic technologies, while ignoring the existing problems concerning enhancement. At the same time, it forces us to go further than the business-as-usual scenarios and take serious the radical visions of the future while talking about current everyday technologies. In the next two sections, we aim to strike such a balance. The next section puts the current upcoming debate on human enhancement within a broader historical context. Grand and compelling visions on the future of science and mankind play a central role there. Section 4 complements the big story by taking a closer look at the development of four specific enhancement technologies: Ritalin, Deep Brain Stimulation, gene doping and designer babies.

### 3. The big picture

- Today we are in the early stages of an epochal shift that will prove as momentous as those other great transformations. This time around, however, the new techniques and technologies are not being applied to reinventing our tools, our methods of food production, our means of manufacturing. Rather, it is ourselves who are being refashioned. We are applying our ingenuity to the challenge of redesigning our own physical and mental capabilities.

Historian Michael Bess (2008) in *Icarus* 2.0



It seems that over the last decade there has been a rather sudden realisation among many intellectuals that what is at stake with regards to current technological development is nothing less than the future of human nature. The journalist Garreau (2004) tells in his book *Radical evolution* that he was looking for the great social changes that would be caused by the Internet and the World Wide Web. During his search he realised that the story he was covering was not about computers: "It is about the defining cultural, social and political issue of our age. It is about human transformation" (Garreau 2004: 11).

It is this common understanding – or maybe rather intuition – that we are living in historical times that creates a new way of looking at our world, a new political reality. Dealing with this reality leads to reflection, plans to boldly move forward, but also unease about the journey we are travelling. On the one hand, our modern technologies fill us with gratefulness because of their power to make life easier, and to empower and heal us. But now we are also starting to realise that our technologies may have unforeseen long-term effects. For example, technologies of healing may also be used to improve our performances. As Bunting (2006) explains: "Much of the research that could be ultimately used for human enhancement is urgently needed to counter such neuro-degenerative diseases as Alzheimer's. But it's all too possible to envisage how fast, in a competitive, unequal world, we could hurtle towards horrible futures."

But is human enhancement really a new phenomenon as the historian Bess suggests at the beginning of this section? And should we consider enhancement as normal, dangerous or overall beneficial? Why is there a growing awareness about human enhancement at this specific moment in time? This section reflects on these questions. It tries to reveal the history of human enhancement, by describing the cultural, technological and political drivers behind it. Because these drivers mutually shape each other – they co-evolve - the description of these three driving forces will overlap.

#### 3.1. Old authoritarian bio-politics

Although human enhancement has become a topic of public and political debate only very recently, it is by no means a recent topic of imagination and reflection. In fact, improving the human condition is the central moral thrust behind the enlightenment, and human enhancement has always been an integral part of it.

### Enlightenment ideals

Descartes (1596-1650) was one of the first to extend the idea of a machine into the domain of living organisms (cf. Noble 1997: 173). In the same era, the English politician, scientist and philosopher Francis Bacon imagined that it would be possible to renew and remake life. In 1627 he wrote his utopian *New Atlantis*, in which he envisioned man flying like birds, people using telephones to communicate with each other over long distances, chickens as big as humans so people would no longer have to suffer from hunger, and influencing human behaviour by means of chemicals. In order to improve the human condition, Bacon promoted an instrumental vision on science. This interventionist ideal – to change the world for the better – still characterises modern science. *New Atlantis* shows that “the thrust behind this new science was not only epistemological but also moral” (Taylor 1991: 104).

### Evolutionary theory

During the 19<sup>th</sup> century many of the technologies envisioned by Bacon became realities: electrical telegraph, steam engines, to name a few. This era also saw many discoveries in the field of biology: think of Pasteur’s germ theory, Darwin’s theory of evolution, Mendel’s hereditary laws (which only became widely known in the early 20<sup>th</sup> century), and the arrival of synthetic (organic) chemistry. These discoveries gave new impetus to Bacon’s dream of the technological dominion over life.

In particular, Charles Darwin’s *Origin of the species* (1859) introduced a radically new perspective on the history and position of mankind. Man was seen as part of the animal kingdom, directly related to animals via genealogical trees. Moreover, since evolution never stops, it became conceivable that man was not the ‘perfect’ end point of history – or better: Darwinism taught that thinking in a teleological way about nature, which now includes thinking about man and his (natural) history, was fallacious.

### Authoritarian eugenics

This evolutionary view inspired the development of *eugenics* as a way of scientifically improving the genetic quality of the human race. Drawing on the work of his cousin Darwin, Sir Francis Galton first coined the term in 1883. He formulated the social philosophy of eugenics, which advocates the improvement of the genetic constitution of the human species by controlled selective breeding (cf. Galton 1907). Some major concerns were intelligence and the elimination of hereditary diseases. Eugenics became an academic discipline and found broad political support, both from the left and right side of the political spectrum, in Western societies in the early decades of the 20<sup>th</sup> century. In many countries the idea was embraced that the state has a certain responsibility in improving the genetic quality of the population and a need too, given the competition with other nation states. This led to what has been called ‘authoritarian eugenics’, essentially led by state agencies. In the United States, Indiana was the first state to legally mandate the sterilisation of ‘confirmed’ criminals, rapists, ‘imbeciles’, and ‘idiots’ in 1907.<sup>1</sup> Various other American states, and countries, like Sweden, Canada, Japan, and of course Nazi Germany would follow with various interventions; ranging from family planning, forbidding abortion by ‘fit’ women, compulsory sterilisation of ‘unfit’ men to even genocide.

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1 <http://www.kobesent.com/eugenics/timeline.html>



### Bio-dreams and transhumanism

The word transhumanism evolved as part of the discussion around eugenics and the social meaning of biology. In 1923, the biological researcher Haldane reflected on the importance of biology for the future in his essay *Daedalus, Science and the Future*. J.B.S. Haldane praised the eugenics movement for preparing public opinion for what was to come and having discovered the significance of biology. Nevertheless, he saw eugenics as a “very crude condition to the production of a race of super-men”. He pictures a future in which humans take control of their genetic future, medicines that stimulate imagination without side-effects and deal with perverted human instincts, and human embryos being bred outside the mother womb (so-called ectogenesis). In hindsight, the biological researcher Haldane anticipated the modern life sciences, and is seen as one of the first intellectual precursors of transhumanism (cf. Hughes 2004). His friend Julian Huxley actually coined the term a few years later in an essay on humanism:

- “The human species can, if it wishes transcend itself – not just sporadically, an individual here in one way, an individual there in another way, but in its entirety, as humanity. We need a name for this new belief. Perhaps *transhumanism* will serve: Man remaining man, but transcending himself, by realising new possibilities of and for his human nature.” (quoted in Hughes 2004: 158) ●●

### Brave New World

Bertrand Russell was more sceptical about the future. In 1924 he responded to Haldane's optimistic lecture on the future of the bio-sciences. In his essay *Icarus or the Future of Science*, he agrees with Haldane's scientific forecast. For example, Russell (2005: 55) had little doubt that physiology in time would find ways of controlling emotion. However, Russell was pessimistic about the way this scientific progress would be used. He feared that science, rather than making men happy, would be used to promote the power of dominant groups ‘beyond dreams’. “Technical scientific knowledge does not make men sensible in their aims, and administrators in the future, will be presumably no less stupid and no less prejudiced than they are at present.”

Aldous Huxley, Julian Huxley's brother, was also worried about the future of the bio-sciences. In 1932 he published *Brave New World*. In this science fiction story a totalitarian regime uses biotechnologies to create social stability. Genetically ideal alphas, cognitively and physically arrested gammas, deltas, and retarded epsilons are all designed to know their place and function in the social order. Human embryos are bred outside the mother womb, and are genetically engineered and socially conditioned in test tubes. Moreover, the state has a medicine that causes instant happiness (soma). This makes *Brave New World* a world without psychic suffrage, diseases, social conflicts, and full of good sex. Nevertheless, the reader realises that the people in this world have lost their families, their ability to love; in short, they have lost their human dignity.

## The Holocaust

Both Russell and Huxley thus turned around the original promises made by Bacon, Galton and Haldane by presenting them as a horror scenario. Both warned for the misuse of modern life sciences by powerful groups and/or totalitarian regimes. *Brave New World* represents a form of authoritarian eugenics. Tomasini (2007) explains that the moral image presented by Huxley is of 'normal man' where social solidarity is engineered to eradicate and/or effectively marginalise individuality. The real future would unravel a different kind of horror scenario. In contrast, eugenics in Nazi Germany was guided by the image of the superior Aryan superman. This *Übermensch* implied an inferior *Untermensch*, who was to be eradicated through sterilisation and extermination. This ideology fuelled the monstrous Nazi race hygiene project, which led to the killings of millions of Jewish people. One of the world's responses to these horrors of the Second World War was to write the Universal Declaration of Human Rights in 1948.

Through the horrific experience of the Holocaust eugenics became a contaminated word. As a practice, however, eugenics has persisted to the present day. As Crook (2008: 135) holds "In welfarist Scandinavia, eugenics has been repackaged as reproductive autonomy or "medical" measures. In Communist China it is alive and well in sterilisation programmes and the one baby policy. More than this, critics allege, it has been resurrected in the "new genetics" of recent times." According to Tomasini (2007: 498-499) also human enhancement should be regarded as a 'neologism': "Calling it enhancement rather than eugenics is partly a rhetorical attempt to disassociate it from the controversy that surrounds the older eugenic debates". In the next section, we will further explore the historical, but also technological roots, of the current debate on human enhancement.

### 3.2. Modern liberal bio-politics

The rise of the modern life sciences predicted by Haldane, really took off after the Second World War. The philosopher Hannah Arendt (1958) sensed its arrival in her book *The Human Condition*, in which she argues that science has found a new domain to master: human life itself:

- "This future man, whom the scientists tell us they will produce in no more than a hundred years, seems to be possessed by a rebellion against human existence as it has been given, a free gift from nowhere (secularly speaking), which he wishes to exchange, as it were, for something he has made himself." (Arendt 1958: 2-3) ●

In line with Arendt's perception, Merelman (2000) points at the historical fact that after the Second World War the focus of technological intervention radically changed. Before the war the focus was on so-called modern industrial technologies, after the war the focus shifted towards post-modern technologies. Whereas modern industrial technologies are aimed at controlling 'nature', post-modern technologies in the information age are directed towards controlling human nature. Technologies that play a central role in the information age are genetics, neurology, pharmacology, medical technology and information and communication technology (ICT). These focuses on our memory and personality, human reproduction and physical achievements; in other words the fundamentals of social interaction, life and human consciousness.

Merelman (2000) explains that there is not a sharp, definitive chronological break between the modern and post-modern culture. "Most important, the post-modern focus on human life merely extends the modernist attention to nature. Post-modern technological culture simply treats human beings as part of nature." As a result, information society contains a broad and novel research agenda for government and science. The research has led to many scientific discoveries, like: the double helix structure of DNA in 1953, recombinant DNA technology, in vitro fertilisation, cloning of mammals.

### AG: After the Genome

The Human Genome project is the latest showpiece of this type of research. This massive government-initiated research program has the same status as the Manhattan-project in the 1940s or the Man-on-the-Moon project in the 1960s. But instead of being directed toward the control of nature it is about the comprehension of the self (Cook-Deegan 1994).

The symbolic meaning of (the technological success of) the Human Genome project should not be underestimated. This milestone in human history finishes a quest for the hereditary traits of human beings that started with the discoveries of Darwin and Mendel in the 19<sup>th</sup> century. It also creates a starting point or better springboard to explore the post-genomic era, and look for new frontiers. This imaginary creative space has been filled up in several ways over the last decade. It unleashed a tide of (bio) technological optimism. Most notably the notion of technological convergence forms the basis of the future vision of scientific mastery of life. This new techno-optimism gave new credibility and impetus to a modern type of transhumanism, which on its turn has stimulated a debate on the pros and cons of human enhancement. We will first shortly describe the history of technological convergence from the perspective of information technology.

### NBIC convergence for improving human performance

For some decades, convergence has been a familiar term within the information technology (IT) sector. During the 1980s the term was used more and more to grasp the automation in industry. For example, mechatronics combines the words mechanics and electronics, and points at the convergence of IT and production processes. The abbreviation ICT refers to the convergence of information processing and communication during the 1990s, which made possible the arrival of the Internet and mobile telephony. Today we are witnessing the rapid integration between these two technological systems. The IT sector refers to this phenomenon as digital convergence, which entails such applications as Voice over IP and watching TV on your mobile phone, and using your mobile as a digital wallet.

In the mid-1990s, when the convergence of information and communication technology and its impact on all kinds of economic sectors was already widely recognised, Castells added a new insight to the notion of convergence. Inspired by Kevin Kelly's book *Out of control: The rise of the neobiological civilisation*, he noticed that information technology and biology were converging.

- "Technological convergence increasingly extends to growing interdependence between the biological and microelectronics revolutions, both materially and methodologically." (Castells 1996: 63) ••

At the time this was best illustrated by the success of the Human Genome project, which depends heavily on bio-informatics. In more abstract terms: the convergence of biotechnology and information technology. During the second half of the 1990s, research institutes, like NASA, began to conceive this convergence as the next phase in the information revolution. Nanotechnology, in particular new materials trends, was seen as an enabler for this fusion of the digital and the biological revolution. The NSF workshop *Converging technologies for improving human performance* (Roco and Bainbridge 2002) which was organised at the end of 2001 brought these ideas under the attention of a broader public.

At the NSF workshop Roco and Bainbridge, the designers of the *National Nanotechnology Initiative*, defined NBIC convergence as the synergistic combination of four major provinces of science and technology: (a) nanoscience and nanotechnology, (b) biotechnology and biomedicine, including genetic engineering, (c) information technology, including advanced computing and communications, (d) cognitive sciences, including cognitive neuroscience. The inclusion of the latter recognises the rapid rise of the cognitive sciences, which includes the strong come back of the artificial intelligence field and the metaphysics behind it (cf. Noble 1997). The NSF expects that through NBIC convergence the technological means to intervene in the human body will rapidly increase; not only by means of biotechnology, but more and more also by computer technology. Moreover, not only our bodies, but also our minds will be the object of intervention.

### Synthetic biology and the aim to master life

- “We have spent billions to unravel our biology, not out of idle curiosity, but in the hope of bettering our lives. We are not about to turn away from this.”

Gregory Stock (quoted in Garreau 2004: 115)



Synthetic biology is a rapidly evolving new research venue, which builds on the idea of convergence, between biotechnology, information technology and nanotechnology. The aim of this new field is to radicalise genetic engineering. Inspired by the ultimate goal of nanotechnology – controlling matter at the atomic scale - the focus is to design and build new biological parts and organisms, or modify existing ones to carry out novel tasks. As Craig Venter, one of the key players in mapping the human genome, put it: “We are moving from reading the genetic code to writing it”. In 2002 the Spanish flu virus was synthesised. At the moment the Craig Venter Institute is about to build the first form of artificial life: the synthetic bacteria *Mycoplasma genitalium*. Analogous to Dolly, the cloned sheep that led to a worldwide debate on human cloning at the end of the 1990s, the environmental movement has already nicknamed this first synthetic life form *Synthia*.

According to various synthetic biologists *Synthia* is just a first small step into the new arts and craft of constructing life. Chris Voigt expects that the first artificial human chromosome will be built in 2014. Another renowned synthetic biologist, Drew Endy, predicts it will be possible in 2012 to construct the chromosomes of mammals. These types of forecasts refuel the dreams of Gregory Stock, who sees human genetic engineering as the inevitable outcome of the decoding of the human genome. In his book *Redesigning Humans*, Stock (2002) described in the idea to add all kinds of traits to animals and people by means of an extra artificial pair of chromosomes. Recently, Freeman Dyson (2007) even goes a step further. In his essay *Our biotech future*, he describes how biotechnology will

change over the coming decades into a garage technology, just like information technology did during the last three decades.

In short, the Human Genome project stimulated scientists and visionaries to think into the future and also gave legitimacy to a new type of bio-futurism. Its central tenet is that “the goal of scientific research and technological development changes from discovery and mapping to constructing and design.” (Van Est et al. 2006) Physicist and futurist Michio Kaku (1998) puts it like this: we are leaving the “age of discovery” in science, and are entering the “age of scientific mastery”. It is exactly this belief that the era of (human) genetic engineering had begun in earnest that has germinated new scientific visions and programs and a social debate on human enhancement.

### Modern liberal bio-politics

- The Biotech Era will bring with it a different constellation of political visions and forces, just as the Industrial Age did. The current debate over embryo and stem cell research already is loosening the old political allegiances and categories. It is just the beginning of the new politics of biology.

Jeremy Rifkin (2001)



NBIC convergence thus raises high expectations. A new wave of technological progress is bound to increase the technological possibilities to intervene in micro-organisms, plants, animals and human. The anticipated set of options raises important ethical and political questions. How to use these future technologies and where to set limits? In the wake of the NBIC workshop a public debate has emerged around human enhancement. This debate seems to follow directly in the footsteps of the biotechnology debates of the last decades. However, it broadens that debate in two fundamental ways. First, from a technological perspective, next to genetic engineering, computer technology, nanotechnology and cognitive sciences enter the game. This is exactly what constitutes NBIC. This also implies that besides the human body, the brain has become central stage as an object of intervention.

From a political standpoint, one might argue that the new and explicit focus on human enhancement politicises the debate, in a way that reminds of the bio-politics that surrounded the eugenics movement. The last few decades has seen many political struggles over genetically modified food and animals, abortion, stem cell research, in vitro fertilisation, cloning at cetera. Most of these struggles are being fought out under the umbrella of bio-ethics in ethical commissions and small circles of academia and think tanks. Until recently, most bio-ethicists' attention was on protecting the public from side-effects of science, like protecting patients against unethical research, possible dangers of in vitro fertilisation. Hughes (2004: 61) calls this proto-bio-politics, and expects that these types of discussions will more and more reach the broader public and become bio-politics proper.

This is because within the current debate a new voice is growing, which is about securing the public's right to science and technology. That political voice is most prominently brought into the debate by the so-called transhumanists. They advocate “the right for those who wish to use technology to extend their mental and physical capacities and improve their control over their own lives” (Hughes 2004: 177). In particular in the United States, a loose transhumanist coalition, advocating for the right to become more than human, populate one extreme side of the bio-political spectrum. Some prominent

advocates of transhumanism are the visionary scientists Eric Drexler (1986), Ray Kurzweil (1999) and Gregory Stock (2002).

This important argumentative shift re-introduces eugenics into the debate on (bio) technology, and makes it truly political. Some authors speak about the revival of eugenics, or the 'new' eugenics (cf. Agar 2004, Crook 2008). Tomasini (2008) explains that the 'new' eugenics can be characterised as liberal eugenics, which emphasises that it is individual free choice that should determine what constitutes human enhancement. Underlying this vision is the idea that there are many distinct ideas about the human good life. In this way the 'new' liberal eugenics distances itself from the 'old' authoritarian eugenics.

Instead of talking about eugenics, the predominant talk is about human enhancement. With regards to human enhancement the term "eugenics", however, no longer covers the whole debate. As described above, NBIC convergence for improving human performance is not only about genetics or biotechnology, and / or directed towards genetic traits. In addition, IT and the cognitive sciences deliver technologies that can enhance humans in different ways, for example through brain implants. This 'technological' broadening of the political debate is one of the key-characteristics of the current discussion on human enhancement. Therefore, we will not speak about the revival of eugenics. Although a major part of the current debate, the 'new' liberal eugenics, it still is just a part of the discussion. Instead, we prefer to use the more inclusive term "bio-politics". Actually, many authors signal the revival of bio-politics (Rifkin 2001, Fukuyama 2002, Hughes 2004, Van Est et al. 2006). As suggested above, modern bio-politics is currently being developed under a liberal political climate.

### Modern utopian transhumanism

In section 3.1 it was described how the term transhumanism developed in the wake of the eugenics movement at the beginning of the 20<sup>th</sup> century. Transhumanism then had a futuristic, optimistic and liberal touch to it. At that time transhumanism anticipated modern bioscience. Modern transhumanism has developed into a political movement, which advocates a rather extreme form of liberal bio-politics.

As a modern politico-philosophical movement transhumanism has its roots in Californian libertarianism, with its faith in technology, the free-market and minimum government intervention. As such transhumanism was part of the counter-culture. Writer and futurologist Fereidoun M. Esfandiary, better known as FM-2030, published in 1973 the influential book *Up-Wingers*. Inspired by the success of the American space program and the birth control pill, Esfandiary claimed that the transition from human to transhuman was already happening (Klerkx 2006). The anti-conception pill was regarded as radical technology that uncoupled erotica from procreation, and gave women control over her own body or nature. In 1967, the Dutch feminist Joke Smit (1967) had heralded the birth control pill as a mighty ally, and described its meaning in Darwinian and transhumanist terms: "Finally women are detached from the rabbits."

Its completely optimistic belief in scientific progress would stay a hallmark for most of transhumanism to come. Throughout the 1980s and 1990s transhumanism stayed a very marginal movement. During that period, the *Extropy Institute*, established in 1988, was one of the most influential transhumanist organisations. Its founder Max More, was inspired by information technology, and believed in virtual immortality. He captured the potential of the California-based net culture, the optimism of the Internet economy, and the World Wide Web to spread the transhumanist message. Next to More's libertarian



transhumanism, a more European style liberal democratic transhumanism developed within the *World Transhumanist Associations* (WTA), which became established in 1997, by the Swedish philosopher Nick Bostrom. The WTA gives serious attention to the social challenges that are associated with their vision. James Hughes, the executive director of WTA, states for example that improving humans must go hand in hand with a radical strengthening of democracy. The decoding of the human genome gave new impetus to transhumanism (cf. Klerkx 2006). The NSF workshop on *Converging technologies for improving human performance* in 2001 seems to proof this point. It also shows that transhumanism embraces with both hands the vast array of technologies that are promised through NBIC convergence.

### Modern dystopian bioLuddism

In America a loose coalition of groups, ranging from (religious) conservatives to disability and environmental activists, severely criticise transhumanism. These so-called bioLuddists, as the transhumanist Hughes (2004) names them, are fearful of various dystopian futures. Bill Joy, chief scientist of Sun Microsystems, was one of the first scientists to ring the alarm bell. Worried by the radical predictions of Kurzweil (1999) and Drexler (1986), he wrote the essay *Why the future doesn't need us* in the April 2000 edition of *Wired*, a magazine for the techno-optimists. Already in the first sentence, the famous computer scientists draw attention to the ultimate doom scenario: "Our most powerful 21<sup>st</sup> century technologies – robotics, genetic engineering, and nanotech – are threatening to make humans an endangered species." Joy's key argument is that these new technologies bring processes of self-reproduction and evolution within the realm of human intervention. He is worried about their impact on human nature and humanity, and calls for a 'period of reflection'.

The emerging bioLuddite coalition includes people from both the Left and Right wing of the political spectrum. At the Left, one can find the anti-corporate ETC group that opposes genetically modified food and asks for a moratorium on nanotechnology, and McKibben (2003), an environmentalist who published the book *Enough*. The ETC group (2003) fears a *Brave New World* type of society in which elites use NBIC technologies to control the masses. In particular in the United States, the (religious) conservatives present a politically influential segment of the bioLuddite coalition under the Bush administration. Fukuyama was one of the neo-conservatives that Bush appointed as member of the President's Council on Bioethics. In his book *Our posthuman future*, Fukuyama (2002) fears that enhancement would threaten the equality of humans. He also wants to prevent a *Brave New World* scenario.

### 3.3. Connecting current and future debates

This section put the current debate on human enhancement in an historical perspective by contrasting old and modern bio-politics. Both forms of bio-politics relate to the enlightenment project. Old bio-politics developed at the end of the 19<sup>th</sup> century. The debate was driven by the authoritarian eugenics movement, who saw a role for the state in improving the genetic quality of the human stock. Authoritarian eugenics found broad political support in many Western countries. The Holocaust gave eugenics a very bad name; eugenics was pronounced taboo.

More than half a century of developments in the life sciences, notably the Human Genome project, has brought eugenics back into the spotlights again. This time it is about non-authoritarian liberal eugenics, but instead of that word the term human enhancement is used. Moreover, new visions, like NBIC convergence, make it clear that besides genetics, other types of biotechnologies, information technologies and cognitive technologies can be



used to improve human performance. In order to encompass this broad spectrum of enhancement technologies into our discussion on human enhancement, we choose to use the broader term liberal bio-politics instead of liberal eugenics.

The symbolic significance of the NSF workshop was that it bluntly revealed human enhancement as a (potential future) core objective of publicly funded science in public. No longer was improving human performance positioned as a peripheral phenomenon. The political message was that it has become less and less legitimate to denote human enhancement as an unintended consequence. No wonder, more and more analysts, like Merelman (2000), Toffler (2000), Garreau (2004), and Bess (2008) even began to see human enhancement as the core aim of the scientific endeavour in our information age. Therefore, we have to accept and morally respond to the insight that our technologies of healing more and more are becoming technologies for human enhancement too. Of course this fundamentally challenges politics. It signals the return of bio-politics, a new demarcation line for the politics of the 21<sup>st</sup> century (cf. Hughes 2004).

This modern liberal bio-politics is guided by utopian views, like those of transhumanists, and dystopian ones, like those expressed by Joy, McKibben and Fukuyama. Hope and belief in technological progress go hand in hand with fear and cultural pessimism about the misuse of technological power. Achterhuis (1998) called this the utopia-dystopia syndrome. By sketching extreme future versions the political discussion about the present and future of our information society gains new meaning. In this way 'new' deep normative questions are put on the front, like what does it mean to be human. The utopia-dystopia syndrome, therefore, is productive in the sense that sharpens the political discussion – it makes it political! – and clarifies the deep normative issues at stake. Its weakness, however, is that it entails a strongly polarised ideological debate, mostly about technologies that do not yet exist in material reality, but in the form of dreams. This is a perfect formula for an endless dialogue of the deaf.

The conclusion at the end of section 2 provides a way out of this trap. It was stated there that the debate on human enhancement technologies demands reflection that is going back and forth into the past and future. It is important, therefore, to connect the futuristic debate, that dominates the big picture of human enhancement, with current social practices in which enhancement technologies play a role, and the debates surrounding them. That is exactly what we plan to do in the next section, where we will describe four small stories about human enhancement technologies. These four cases will hopefully give a better insight on how the new liberal bio-politics gets shaped.



## 4. Four small stories

This section describes four short case studies on human enhancement. For selecting the cases we started from the notion of NBIC convergence. The cases, therefore, are drawn from the three areas that play central stage in the current discussion on human enhancement: besides genetic engineering, we include pharmaceuticals, and neuroscience (and its intersection with the technologies of prosthetics, robotics, and artificial intelligence). The four cases are: the drug Ritalin, Deep Brain Stimulation by means of electrodes in the brain, gene doping, and pre-implantation genetic diagnosis (PGD).

As argued in section 2, we will look at the history of these technologies, the present, and the expectations about the future. For example, in the description of the PGD case will also include the discussion and regulation of in vitro fertilisation (IVF), since this is “the core technology upon which all of these new and controversial reproductive and genetic technologies are based” (Throsby 2004: 191) The case description will pay due attention to the social, cultural, and economic context in which the human enhancement technologies develop. It also looks at the societal and ethical issues that are raised by these technologies, and the way in which these issues are dealt with, for example via regulation, or not. In this way, the various cases will illustrate how the new liberal bio-politics is developing within different social contexts.

### 4.1. Ritalin

The drug methylphenidate, better known by its commercial name Ritalin, is a so-called dual-use drug: a drug that is used for therapeutic, but also for enhancement and recreational ends. The latter usage is because Ritalin chemically resembles cocaine, and if snorted or taken intravenously it has similar effects as cocaine. Taken orally in the form of a pill, the drug is either used therapeutically for the treatment of people diagnosed with Attention Deficit / Hyperactivity Disorder (ADHD) or used for the enhancement of attention in normal subjects. Eighty percent of therapeutic users is male, most of which are boys. In recent years the number of patients diagnosed as having ADHD has increased strongly. The diagnosis has also widened to girls and adults. Because of Ritalin’s alleged potential to promote concentration it is often earmarked as a “universal performance enhancer”. Namely, improved concentration is taken to enhance performance on all tasks that critically imply cognitive function. This makes Ritalin a candidate for cognitive enhancement. The usage of Ritalin among American students to enhance their learning capabilities (as well as to get high) is widely reported. This case study will investigate what kind of issues the Ritalin gives rise to, from the perspective of human enhancement.

#### Therapeutic use ...

Ritalin and ADHD provide fascinating histories, which are illustrative for the history of psychopharmacology and psychiatry in general. The latter shows an interesting dynamics, moving from a biological orientation at the beginning of the 20<sup>th</sup> century, to a psychodynamical orientation and back to a biological orientation during the last decades of the 20<sup>th</sup> century. The success of a number of psycho-pharmaceuticals, like chlorpromazine (for schizophrenia and psychotic disorders), Ritalin and fluoxetine hydrochloride (i.e., Prozac, for depression), played a key role in the come-back and current victory of the biological orientation. More specifically, the availability of a psycho-pharmaceutical that was able to alleviate concentration seems to have played a major role in the medicalisation of lack of concentration and hyperactive behavior of children.



The following logic lies behind this medicalisation: if a drug can restore “normal behavior”, then the pre-medicated behavior must have been not merely deviating, but pathological *and* must have been caused by some neuro-chemical imbalance. Psychiatry’s history proves such reasoning to be enormously powerful, also where it comes to ADHD and Ritalin (cf. Shorter 1997). Hence medicalisation and somatisation (the localisation of a behavioral deviation in some bodily substrate) of inattentive and hyperactive behaviors has taken place, despite the fact that the physiological causes of ADHD are still unknown and ‘[n]o validated diagnostic test exists to confirm the clinical diagnosis’ (Zwi et al. 2000, 975). The opinions on the causes of the behavior indicative of ADHD differ enormously. They range from neurological dysfunction to hearing impairments and from lack of sleep to psychologically disturbing events such as the death of parents or siblings (cf. Bailly 2005; O’Brien et al. 2003; Van den Berg & Marcoen 2004; Bennet & Haggard 1999). Because so many different causes are associated with ADHD some people question whether its symptomatic behaviours are really indicative of one discrete disorder. Some have put forward the possibility that ADHD is not *one* disorder, but rather a catch-all diagnosis that covers several disparate psychological deficits, that might each have their own neurological cause (cf. e.g. Zwi et al. 2000: 975; Reason 1999). Also where it comes to ADHD’s treatment with Ritalin uncertainty exists, as the exact neurological workings of Ritalin is unknown. Nevertheless, ADHD is now commonly considered to be a neuro-developmental disorder, and the prescriptions of Ritalin for the treatment of ADHD have been rising ever since its launch at the beginning of the 1980s. In many European countries today around five percent of children are diagnosed with ADHD, but epidemiological studies have produced prevalence estimates ranging from one-half to twenty-six percent (Timimi 2004). In the United States seven percent of all children between three and seventeen years are diagnosed with ADHD (Bloom et al. 2006), whereas in Italy hardly any psychiatrist recognises the diagnosis as valid (Brancaccio 2001).

Around the time Ritalin hit the market, the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) was introduced. The DSM-III (1980) dramatically changed the way psychiatric disorders are classified, and gave credibility to the above logic. The objective of DSM-III was to turn psychiatry into a rigorous science. It wanted to leave behind psychiatry’s associations with vague and speculative psycho-dynamical ideas. As a result, DSM’s third edition removed any reference to psychiatric disorder’s alleged “causes”. Diagnosis had to be based on readily perceivable phenomena only, leaving out everything speculative, such as (unconscious) motivations, drives and emotional forces. For example, diagnosis of ADHD is based on three symptomatic behaviors: inattention, hyperactivity and impulsiveness. Ritalin or similar psycho-stimulants are its commonest treatments. By the way, the DSM-III also introduced ADHD’s direct predecessor Attention Deficit Disorder, only to make place for (the less restricted) ADHD in its 1994 issue IV. During the 1970s, it had been common practice to refer to this disorder as either “Hyperkinetic Reaction of Childhood” (if one was psycho-dynamically-minded) or “Minimal Brain Dysfunction” (MBD) (if one was biologically-minded). Since from DSM-III onwards diagnosis had to be based on outwardly observable phenomena only, there was neither place for “Hyperkinetic Reaction of Childhood” nor for MBD in the DSM’s psychiatric classification (cf. Brancaccio 2001, Rafalovich 2001, Singh 2006).

### ... And its ongoing controversy

Despite the commercial success of Ritalin, its prescription has remained controversial throughout the years. There is disagreement about whether or not these behaviors should be treated pharmacologically, and whether they belong to the psychiatric realm altogether. Proponents see Ritalin as a miracle drug and argue that ADHD is under-diagnosed and under-treated (e.g. Barkley 1997). Opponents argue that ADHD is over-diagnosed and over-treated. They are concerned about the long-term effect of its widespread use. They even fear that Ritalin may disrupt normal child development, and also worry about the consequences for society as a whole.

The critics claim that the diagnosis of ADHD requires difficult normative judgments throughout. The diagnosis is ambiguous: what one person might consider to be inattentive, hyperactive or impulsive behavior symptomatic of a psychiatric disorder, another might perceive as healthy boyishness. This makes Singh (206: 439) state that, ADHD, more than any other diagnosis on the medical market today, “problematizes the assumption of an objective measure of ‘normal’ functioning, and points to the distinctly social task of judging normative behaviors, assigning diagnostic labels and deciding on, and responding to, medical treatments (ibid.)

The complex issue of whether ADHD is really a viable, medical diagnosis directly leads to the question of whether this disorder is caused by a neurological defect or social problems or the interaction of both. This brings up the issue of whether a pill is the right way to treat ADHD. Critics claim that the use of Ritalin prevents modern society to address the real social problems at stake. For example, some see Ritalin as a dangerous drug, which offers bad teachers and parents an easy way to discipline their unruly boys (e.g. Breggin 1998). Neuro-scientist Steven Rose worries about the long-term social implications and fears that modern society is opting for quick technological fixes. According to Rose (2006): “The growing belief in a ‘pill for every ill’ ignores the ways that a child’s discontent at school might be caused by a poor home environment, inadequate teachers, rigid syllabuses or even endemic racism. We seem to be heading towards a pharmacologically defined future”. In this view, the use of Ritalin is seen as forced upon society, and that it is only for Big Pharma to make large profits.

### Enhancement use

A famous study by Rapoport *et al.* in 1978 - which today to all likelihood wouldn’t pass medical-ethical boards - showed that methylphenidate-like agents do not merely alleviate attention and composure in subjects who suffer from ADHD, but also, and even to a larger extent, in subjects who do *not* suffer from such complaints. Moreover, people with higher than average learning skills seem to benefit most from the use of methylphenidate-like pharmaceuticals for their (cognitive) achievements. This makes Ritalin (and comparable substances) a likely candidate for being considered a human enhancement technology. Indeed, its use by college American students’ writing papers or learning exams is widely reported.

The enhancement use of Ritalin by students has raised the issue of fairness: in a world in which competitive advantage is very much dependent on scholarly results, those with access to Ritalin to enhance their concentration when doing exams seem to have unfair benefits relative to those without access to Ritalin. This gives rise to several questions, two of which Turner and Sahakian (2006: 84) formulate as follows:

- “Is it possible that these drugs could be used to reduce social inequality and injustice in society? Or is it more likely that their use will fuel further disparity based on a lack of affordability?” ●●

Following this line of thought, they speculate about the future prospect of drug-testing regimes in schools, similar to those common in sports, in order to deal with this issue.

### Discussion

The case of Ritalin shows that one pill or technology can be used for a variety of purposes: therapeutic and non-therapeutic, where the latter category can be refined in the two subcategories of enhancement use and recreational use. Focussing on enhancement these different usages lead to partially overlapping and partially distinct moral, social and regulatory issues. From a judicial point of view the therapeutic use of Ritalin is legal, the non-therapeutic is not. Nevertheless, the broad availability of Ritalin, because of its widespread therapeutic use, has unquestionably led to an (illegal) market for its enhancement and recreational use. As POST, the British office for parliamentary technology assessment puts it (<http://www.parliament.uk/documents/upload/postn285.pdf>):

- “Increased availability of cognitive enhancers could lead to greater pressure on individuals to use them. In the first instance, this could arise through pressure to compete with peers at school or in work. Indeed, legislation has already been introduced in the US to prevent school personnel promoting the use of cognitive enhancers. There are also ethical questions as to whether employers would be within their rights to require employees in certain professions to use cognition enhancers in the workplace.” ●●

The legal therapeutic use of Ritalin, however, is also much debated from an enhancement point of view. Because of the fine lines involved in the diagnosis of ADHD, which require normative judgments that are highly sensitive for diverging opinions, it is often hard to judge whether Ritalin is used as a therapeutic or an enhancing agent.

#### 4.2. Deep Brain Stimulation (DBS)

In the 1980s a new neurosurgical technique has been developed to target Parkinson's, Essential Tremor, and other tremor-inducing disorders: Deep brain stimulation (DBS). In DBS a lead with two to four contacts for electrical stimulation is implanted in the brain, connected to a programmable and implantable pulse generator. This “pacemaker for the brain” fires electrical pulses at specific brain areas, which are thought to be implicated in the targeted neurological (or psychiatric) disorder. The DBS's electrodes are connected to wires that run down to a battery-powered pack, which is placed under the clavicle, and can be controlled by the patient. The precise activity of the DBS needs to be worked out. This fine-tuning can take weeks, and even months.

Critical success factors for the expansion of the area of application of DBS are the modern brain-imaging techniques that have been developed during the last decades. CT and (f)MRI have helped establish correlations between various (symptoms of) neurological and psychiatric disorders on the one hand, and (dys)functioning of specific brain areas on the other (cf. Kopell et.al. 2004). Following the identification of relevant brain areas, these areas can be targeted with DBS to treat the correlated disorders—or better: to fight specific symptoms of those disorders.



Neuro-imaging techniques also play a crucial role in the surgical intervention itself, since they are used to make sure where precisely in the particular patient at hand the DBS should be placed, and similarly to ensure that there are no big arteries running through the brain area the electrode has to pass through.

Today DBS is mainly placed in the sub thalamic nucleus and used for the treatment of Parkinson's and other diseases that cause tremor. Currently, around 40.000 people worldwide have a DBS.<sup>2</sup> For Parkinson's fairly good results have been recorded: on average Parkinson's patients report some fifty percent improvement in basic activities such as walking and keeping balance. DBS does not *cure* Parkinson's, it offers a therapy for some of its symptoms (mostly motor-function symptoms). Other symptoms of Parkinson's, such as memory loss, depression or anxiety are not or sometimes negatively affected by DBS.

According to neurosurgeon and DBS-champion Ali Rezai, successful use of DBS for neurological afflictions such as Parkinson's should be regarded as "the tip of the iceberg".<sup>3</sup> Today experiments are conducted with applications of DBS in patients suffering from Gilles de la Tourette (a neurological disorder often associated with psychiatric symptoms) and in psychiatric patients suffering from, e.g., major depression or Obsessive Compulsive Disorder (OCD). However, use of DBS for other disorders than Parkinson's and similar neurological causes of tremor are all still in a (very) experimental phase. To illustrate: as of 2004, no more than a handful of people had been given DBS for Gilles de la Tourette or Obsessive Compulsive Disorder (Van 't Hoog 2004).

#### How does it work?

Interestingly, the success of DBS seems to run out of track with the available knowledge on the mechanisms through which it works. That is to say, there exists controversy about the causal mechanism to which DBS owes its efficacy. It is clear that the electrical activity of DBS changes the local neurochemistry and activity, but precisely how it works remains unclear.

DBS is often regarded as the successor of lobotomy, because it is likely that also this intervention owes its efficacy to a lesioning effect—in other words, it seems that it works through locally blocking neural activity. But whereas lobotomy involved permanently damaging or removing brain tissue, DBS is reversible. This leads to clear optimism among specialists:

- With this technique, we have for the first time in psychosurgery the chance to help patients without damaging their brain in an irreversible way. (Berkelbach van der Sprenkel 2004: 61) ●●

Being relatively benign, however, seems not the sole reason for trying this still risky surgical operation. DBS entails the promise of putting psychiatry on a truly scientific trail, by directly connecting psychiatric illnesses with neurological knowledge, rather than with outward symptoms only. This promise of a thoroughly biologised, evidence-based psychiatry invites the expansion of the (experimental) use of DBS.

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<sup>2</sup> See [http://www.pbs.org/kcet/wiredscience/video/255-deep\\_brain\\_stimulation.html](http://www.pbs.org/kcet/wiredscience/video/255-deep_brain_stimulation.html)

<sup>3</sup> See <http://www.time.com/time/magazine/article/0,9171,1214939,00.html>



### DBS's infamous predecessor: lobotomy

Despite its promises, DBS, being a neurosurgical technique with psychosurgical potential, has a tough stigma to fight against. DBS's predecessor lobotomy has almost generally been abandoned, often enforced by law (Kopell, Greenberg & Rezai 2004). Although this is not the place to unfold the full tale of lobotomy (cf. Diefenbach et al. 1999, and El-Haj 2005), some of its strands are helpful for thinking about DBS.

Lobotomy was first practiced by the Portuguese Antonio Moniz, but was made famous by the American neurologist Walter Freeman, who has performed thousands of lobotomies. Freeman infamously tended to use an ice-pick for the surgical procedure. Rather than the eccentric work of a bunch of mad men, lobotomy at the time was considered state-of-the-art science. The fact that in 1949 Moniz received a Nobel price for his work in lobotomy illustrates this. This does not entail, however, that when measured against today's standards, lobotomy was grounded in rigorous scientific work. Evidence-based medicine did not exist in those days. Moniz, for example, did not present test results of the patients before and after the surgical procedure.

But more reasons can be found for why there is such a bad sound to lobotomy today. For one thing, it appears often to have been used as a cheap and fast solution to difficult and expensive social problems:

- For state hospital physicians working in overcrowded and understaffed institutions, lobotomy provided a scientifically based means by which to treat their most psychotic and uncontrollable patients. (Braslow 1999: 236-7; cf. Lerner 2005)

After lobotomy, namely, many patients were much calmer than they were before and could therefore be cared for much easier, or could even be released from the overcrowded psychiatric wards. Sometimes it was practiced by doctors without surgical training, or even by non-medical hospital personnel (Van 't Hoog 2004: 105). When the first psychopharmaceuticals (such as chlorpromazine) came available in the 1950s, many practitioners stopped performing lobotomy.

Partly in reaction to such aforementioned abuses, regulatory systems, like ethical boards and procedures of informed consent, have been put in place. In the Netherlands, for example, there exist strict conditions for the use of DBS. The patient needs to suffer from the disease for more than five years, while not responding to existing therapies such as psycho-pharmaceuticals. Moreover, there needs to be severe suffering from the side of the patient, with little hope of cure. Additionally, approval for the use of DBS is needed from both the patient and the family. And finally, the whole procedure is tested by a medical ethical commission (Van 't Hoog 2005: 106).

### Risks and enhancement as a side-effect

Like any other (neuro)surgical intervention, DBS is not without risks. Risks common to neurosurgery are hemorrhage and infection—possibly resulting in death (Deuschl et.al. 2006). A variety of side effects of DBS have been reported, ranging from the agreeable—e.g. enhanced mood and uncontrollable bouts of laughter—to the uncongenial—e.g. mania and psychosis. Also suicide seems to be a somewhat regular “adverse effect”: in a cohort of 140 patients treated for Parkinson’s with DBS, 4.3% committed suicide (Burkhard et.al. 2004). One coincidental case is reported of dramatically increased memory: in a subject who got DBS for an experimental trial for the treatment of obesity, memory was, allegedly, significantly enhanced.<sup>4</sup>

Thus we find that enhancement of one or other human trait can sometimes be an unforeseen and unintentional side-effect of the DBS therapy. This shows that with the widespread use of DSB also a new experimental terrain is being developed, which by coincidence might lead to insights on how to enhance various cognitive functions. As many historical cases bare witness to, such serendipity can be a major component of scientific discoveries and progress.

### What is at stake?

Technologies such as these have the power to instantly trigger all kinds of (rush) reactions, both from enthusiasts and from critics. This is especially the case where we witness the move of DBS from neurological disorders (such as Parkinson’s), through intermediary cases (such as Tourette) to psychiatric disorders—in other words: where *neurosurgery* turns into *psychosurgery*. The optimists here see either a potential route for psychiatry finally to become truly scientific, or a highly precise means to enhance all kinds of cognitive functions, or both.<sup>5</sup> For others DBS constitutes a problematic instance of an imperialist drive characteristic of much technology:

- There is nothing particularly sublime or marvellous about this. Instead of liberation and transcendence it invokes the idea of technical dependency and even the scenario of remote-controlled humans – of which we would hardly say that they are enhanced or that they possess extended powers of self-determination, even if we placed the remote-control in their own hands. (Nordmann, n.d.) ●●

For this critical camp it is crucial that such developments allegedly show that our cognition, emotion, perception—our *selves*—have been materialised and mechanised. That is to say, a presupposition underlying much of the debates on the societal and ethical implications of technologies such as DBS is that they manifest that medicine has come to grips with something that was until recently considered to be out of reach of direct medical intervention: *the mind*. Accordingly, so the reasoning goes, the mind has obviously (and finally) become part of nature in much the same way as anything else we encounter in our daily lives. The history of at least the last four hundred years has shown that once *known*, nature can be *manipulated* at will. The capacity of turning on and off emotions, moods, motor control and what have we, simply by switching on or off one’s DBS, appears to powerfully illustrate this enlarged power of science and technology.

<sup>4</sup> See Hamani et.al. 2008. I write allegedly, taking into account all the easily imaginable problems with claims about retrieval of old memories—who can tell whether what you experience as memory are factually how things went at the time?

<sup>5</sup> See e.g. NRC Handelsblad 28 July 2007.



Following this line of thought, the idea of a pacemaker for the brain is easily associated with “emotions on demand” and “cosmetic mental surgery”. It is imagined that what belongs to our cognitive, emotional and perceptive possibilities becomes something that we can choose in a way analogous to how we choose which shoes we wear. Mention is being made of remote-controlled humans, fully dependent on technology, as it is envisioned that by switching one’s DBS on and off at will—at different locations in the brain, in different ways and at different moments—one can control not only tremors, but mood and emotions as well. The sound of contempt that can be heard in Nordmann’s voice in the above quotation speaks from such worries about “instant self-techniques”. What remains of any authentic self, if one’s emotions and moods can be altered by pushing a button?

More practical worries arise when one considers who is responsible for one’s actions, if these can be incited by technology-induced affective responses. Although there seems to quite a huge gap between such worries and the scientific state of affairs, there are clearly moral worries along these lines that are already topical. The aforementioned adverse side-effect of mania, for example, can have severe consequences. Leentjens et al. (2004) describe a Parkinson’s patient who after (successful) treatment with DBS became euphoric and manifested manic behaviours to a very problematic extent. His condition of Parkinson’s was alleviated significantly, but additionally he started an affair with a married woman, bought several houses and several cars – with money he did not in fact have – and ended up with judicial and financial troubles. While his DBS was turned on, he was completely unaware of his manic behaviour. But when it was turned off, he showed awareness and regret. In light of such case description, also the issue of misuse of technologies by powerful actors to control people pops up here.

Informed consent becomes a very difficult notion here, as does moral responsibility for one’s actions. Who must be held accountable for the damage done while his DBS was turned on? The patient, the DBS device, the doctors who implanted it and turned it on? When his DBS is turned off, the patient will likely have his choice on whether to use his DBS or not be informed by his (very bad) Parkinson’s condition. In this case, the patient did indeed choose to have his DBS turned on again. In any case, we find that a piece of technology succeeds to create a moral dilemma and that this technology likely impacts on the outcome of the moral deliberation it puts into working (cf. Verbeek 2008). These and similar questions, so the above description of state of affairs suggests, should be discussed and, more urgently, should find their way into policy-making with regard to the use and abuse of DBS. Common ethical and judicial frames of thought do not seem to have much to offer for thinking about an issue like this, where technology becomes a (moral) player in its own right.

## Conclusion

At this moment Deep Brain Stimulation is not being used to enhance performance of the brain. It is being used for the treatment of Parkinson’s and other diseases that cause tremor. This treatment is strongly regulated. DBS is only used in extreme circumstances: severe suffering of the patient, no alternatives and hope for improvement available. Also the risks of DBS are severe. Think of classical risks like infection. DBS regularly involves rather unpredictable changes in personality traits: from suicidal behaviour to enhanced moods and enhanced memory.





This coincidental deterioration and enhancement illustrates the experimental stage DBS is in right now. Nothing much is known as yet about what we can realistically expect from DBS in the future — not with respect to the range of disorders that will be treated with it, nor with respect to its potential in enhancing memory and moods. Nevertheless, the experimentation in the field of DBS is guided by the hope to make psychiatry science-based. This is being legitimated through the hope to offer release and treatment for very serious neurological and mental disorders. Part of the experiment and the endeavour to create a science-based psychiatry, however, is the expectation that via serendipity scientists will also find out ways to enhance certain brain functions. Accordingly, in the case of DBS there is no clear borderline between science for treatment and science for enhancement.

It is exactly that idea that both attracts and frightens many. It is associated with the loss of authenticity, for example, and immediately elicits generic fears concerning equity. Neuro-philosophers, neuro-ethicists, neuro-sociologists and neuro-jurists are presented with a challenging case to direct their attention to. What to think of *the self* if its essential attributes of mood and emotions can be manipulated at will, by everyone who happens to hold on to the joystick connected to your DBS? Is such manipulation morally permissible? And what conclusions does this entail when it comes to law—who is to be held responsible for behaviour conducted while the mood of the agent at issue was being altered by DBS?

#### 4.3. Gene therapy and doping

Gene therapy entails “the transfer of genetic material to human cells for *the treatment or prevention of a disease or disorder*” (Haisma & De Hon 2006: 259; italics ours). Gene therapy, however, can also be used to enhance someone’s natural endowments. In that case, one speaks of genetic enhancement. Given the continuous strong pressure on athletes to improve their performance, sports might be one of the first social practices to use human enhancement technologies. This section explores the potential use of genetic enhancement in sports, or in short: gene doping.

##### From gene therapy ...

In gene therapy a gene, which can compensate for a missing or abnormal gene, is delivered to a cell nucleus by a so-called vector, usually a non-pathogenic virus. The new genetic material encodes for the production of a certain relevant protein. By means of gene therapy scientists try to cure, or prevent, genetic diseases as severe anaemia, muscular dystrophy, or immunodeficiency. So far few diseases have been cured or prevented through gene therapy (Reynolds 2007). Gene therapy, thus, is still in an experimental stage. There are various risks involved. There is the possibility of auto-immune reactions to the treatment (Haisma & De Hon 2006: 263). Up till now three patients developed leukemia-like symptoms. Also flu-like symptoms have been reported as side-effects.

The use of gene therapy is regulated. In the Netherlands, permission of Central Committee on Research involving Human Subjects (CCMO) and Committee on Genetic Modification (COGEM) is mandatory to start a clinical trial of a gene therapy (Haisma & De Hon 2005: 123). In Europe, the European Council has adopted directives to ensure the containment of genetically modified organisms and to protect the health of those working with biological agents. Good Laboratory Practice (GLP) and Good Manufacturing Practice (GMP) are also mandatory. In Europe, marketing authorisation is covered by the European Medicines Evaluation Agency (Haisma & De Hon 2006: 259), but the exchange – and therefore the availability – of genetic materials is only limited by the EC degree Nr. 3381/94. This limits the import and export of strategic goods, including genetic materials (ibid. 264).



### ... To genetic enhancement in sports

It is expected that gene therapy when used on healthy people will enhance the production of the targeted protein above the natural level. Therefore, gene therapy might enhance the performance of athletes in specific ways. By inserting the gene that is responsible for the creation of red blood cells, erythropoietin, better known as EPO, the aerobic capacity of the muscles could be improved. Muscles could also be strengthened locally by injecting the gene coding for the creation of insulin-like growth factor-1. By blocking the growth-inhibitor myostatin muscle growth could be stimulated. A better blood supply of tissues by newly formed new vessels could delay exhaustion. The gene encoding for vascular endothelial growth factor could be used for this. By genetically enhancing their pain relief system (endorphins, enkephalins), athletes would experience less pain and could perform at their maximum longer at a time (ibid. 261-262). It is important to notice here that all these enhancement options are currently being developed to treat diseases, like severe anemia or muscular dystrophy.

### The pressure to compete, and risks to consider

The physiologist H. Lee Sweeney successfully demonstrated various genetic enhancement technologies in mice, and became the creator of the super-muscular Schwarzenegger-mouse. In 2004, he predicted in the *Scientific American* that the first kind of tissue likely to be subjected to genetic enhancement would be muscle, but that the actual use by humans would be years away:

- The technology necessary to *abuse* gene transfer is certainly not yet within reach of the average athlete. [...] So will we one day be engineering super-athletes or simply bettering the health of the entire population with gene transfer? Even in its infancy, this technology clearly has tremendous potential to change both sports and our society. The ethical issues surrounding genetic enhancement are many and complex. But for once, we have time to discuss and debate them before the ability to use this power is upon us. (Sweeney 2004; italics ours) ●●

Sweeney apparently overlooked the willingness of athletes to try an experimental enhancing technique, which seems rather naïve. For some time, athletes pursuing the Olympic motto 'citius, altius, fortius' ('faster, higher, stronger') have been benefiting from technological innovations. However, not only the athletes' desire to be the very best is responsible for the constant quest for the best method of training, diet, and state-of-the-art equipment. In the world of commercial sports, athletes, their coaches and their sponsors have a lot to gain. However, there is also a lot to lose, since nobody wants their reputation, or their income, tainted by a (doping) scandal.

Of course changing nature does not mean that one can go without nurture (Blitz, 2005, 90). Being in great shape, having a perfect technique or strategic insight, etc. can't be realised through genetic enhancement. To reach the top, years of hard work under the supervision of a good coach are required, which in turn requires character, determination and motivation. Nevertheless gene doping may tip the balance in the right direction, and may mean the difference between winning or losing.

Athletes willing to consider the use of gene doping have to consider some of the above mentioned risks associated with gene therapy. In 2007, Hidde Haisma, professor of therapeutic gene modulation, claimed that manufacturing gene doping is relatively easy and cheap (Van Lare 2007). He stated that any student who has completed an internship at his laboratory can make a gene construct suitable for doping. Implementing the technology into humans, however, still is a very complex and risky task. As Theodore Friedmann, a leading expert in genetic research, states: "The bottom line is that everything gets complicated when you move from the laboratory into a human being. We don't have the technology yet in hand to ensure a predictable and adequate level of safety to feel comfortable using gene transfer technology in anyone other than a patient with a serious or untreatable disease." (WADA 2005: 8)

Administering gene doping illegally to athletes even adds further risks. The genetic material or the virus used in the treatment could be of inferior quality to that used in a controlled laboratory. The virus could be pathogenic and infect the athlete – and possibly other people. At the moment, it is also unclear if and how the genetically enhanced production of muscle or red blood cells can be slowed down again. Unnaturally high levels of red blood cells thicken the blood, which may result in a heart attack or stroke (Haisma & De Hon 2006: 263). Since gene therapy is relatively new, the long and short term effects need to be studied in order to assess the safety of the technology. Nevertheless, for athletes the potential benefits could outweigh the risks involved in gene doping.

### The war against (gene) doping

The world of sports has its own values, habits and rules. The International Olympic Committee (IOC) and the World Anti-Doping Agency (WADA) guard those values and habits, by seeing to it that the rules are complied with. According to WADA's *World Anti-Doping Code* (or the *Code*) the values of sports include fair play, health, and respect for self and other participants (WADA 2003: 3). Since the coming into being of competitive sports, there have been attempts to enhance performance. Some of these attempts involved generally accepted methods or substances, like training or eating healthy, but illegal substances and practices are also used. Using performance enhancing drugs is an example of an illegal practice. To promote the ideal of fair and clean sports, WADA regularly tests athletes to see if they have used prohibited substances, and tries to educate the athletic community about the "spirit of sport", and the dangers of doping.

The WADA was created in 1999 by the IOC, governments and other authorities to promote and coordinate the international fight against doping. Every year, WADA updates a list of substances and methods banned from sports. A substance or method can be included on *The Prohibited List* if it satisfies at least two of the following criteria (WADA 2003: 16, comment 4.3.2):

1. the substance or method is (potentially) performance enhancing;
2. might be dangerous for the athletes' health; and/or
3. it violates the spirit of sports (WADA, 2003, 16, comment 4.3.2).

The WADA included gene doping on the prohibited list since 2003, years before scientists thought it would be possible for athletes to use the technology. WADA (2007: 7) defined gene doping as "the *non-therapeutic use* of cells, genes, genetic elements, or the modulation of gene expression, having the capacity to enhance athletic performance" (*italics ours*). At this experimental stage gene doping fulfill all three criteria. WADA will try to detect gene doping, and punish the offenders according to the usual standards.



Whether athletes are already experimenting with gene doping is unclear. There are no reports of experiments by or on athletes with the technology. Moreover, no athletes have been “caught” so far using or attempting to use gene doping. But that can also be due to the fact that scientists are still developing the test (Ruibal 2005). When the test WADA requested is ready for use, the samples collected in previous years – all collected test samples are frozen and kept for a couple of years in case later (re-)testing is necessary – will be tested.

If a test to detect gene doping cannot be developed, or be developed quickly enough, there is an alternative available. An identity card could be implemented, which can be used to assess and monitor biological, chemical and physical conditions of athletes. Professional cycling already has made the step towards out-of-competition testing. For each cyclist a so-called bio-passport is used. All kinds of physical parameters of the athlete are measured every two months, and administered. Any changes that cannot be explained by training or diet could be reason for further investigation. This might be seen as an alternative way to infer the use of gene doping by the athlete, without actually physically proving it (Austen 2004).

#### Thin line between therapeutic and non-therapeutic use

The WADA definition of gene doping refers to ‘non-therapeutic’ use of genetic transfer techniques. The line between therapeutic and non-therapeutic use of gene therapy is not so clear. Gene therapy could be used to treat sport injuries by stimulating tissue to re-grow. If gene therapy could be used to heal injuries faster, or even allows injuries that these days will end a career to heal, should this treatment be withheld from athletes? Or will such treatment be regarded just as 21<sup>st</sup> century sports medicine?

From an anti-doping perspective a crucial question is whether, if the results of gene therapy are long-term, any athlete who has received gene *therapy* for an illness in the past, which could also have enhanced his performance beyond the athletes’ natural ability, is excluded from competition for life? Is there a point in which “therapeutic” becomes “non-therapeutic”, and if there is, how can an anti-doping policy deal with that? Here the fine line between treatment and enhancement becomes visible. Reflecting on these issues, Theodore Friedman argues that therapy and enhancement are “part of a continuum in which a genetic treatment to heal a short-term injury could also lead to the long-term enhancement of the athlete’s genetic make-up” (quoted in Sandomir 2002). Nevertheless, the demarcation is important for the implementation of an anti-gene-doping policy.

#### Sports in society

Genetic enhancements have the potential to thoroughly change (commercial) sports. Right now, all policies of WADA and the national sports federations are aimed at stopping this development. But WADA can not control the use of genetic enhancement technologies outside professional sports. How will this large gap between sports and society evolve? Let us sketch four possible scenarios. Scenario 1: Less talented, but enhanced, athletes outside professional sports outperform professional athletes. Scenario 2: an “untested, anything goes” league for enhanced athletes exists next to the one for natural athletes that does ban certain substances and methods. Actually, this is already the case in competitive bodybuilding (Garreau 2007). Scenario 3: athletes have to get enhanced to compete, because a new standard will arise. Van Hilvoorde (2004) sees this as a likely scenario. It is conceivable that genetic enhancements – if safe, voluntary and medically supervised – are allowed in sports, just like training and using state-of-the-art equipment are allowed

(cf. Miah 2005, 2007). In a fourth scenario, the rigorous anti-doping policy of WADA is extended towards each citizen.

The voice of the public will likely play an important factor in the future development of gene doping. Will the public turn its back on commercial sports if even more doping is used? Or as professor of health and human development Yesalis (2000) aptly puts it: “do people just want to be entertained, or do they disapprove of doping use enough to actually switch off their television?”

### Conclusions

The development of gene transfer technologies for therapeutic use is in an experimental phase. Only few therapeutic successes have been reported so far. Gene therapy is regulated in various ways. Gene transfer is also expected to enhance the performance of healthy individuals. This option – gene doping - could be attractive for professional athletes. Since the use of this technology could radically change sports, the World Anti-doping Agency (WADA) already anticipates gene doping by putting it on the list of prohibited substances and methods, and by fostering the development of anti-gene-doping tests.

The WADA prohibits professional athletes the non-therapeutic use of gene transfer technologies. The demarcation between non-therapeutic and therapeutic, however, is not a clear cut one. For example, gene therapy may be used to speed up the recovery from an injury, but might also lead to performance enhancement on the longer-term. So within the domain of professional sports the regulation of the use of gene therapy needs to further elaborate upon. Outside the strict and severe anti-doping domain, genetic enhancement is expected to challenge society even more. Taking into account the interaction between sports and society four scenarios were presented that each severely challenge professional sports, but also society at large.

#### 4.4. Pre-implementation genetic diagnosis (PGD)

Gene therapy and gene doping only affect the genetic material of the individuals who undergo them. In contrast, affecting the genetic make-up of embryos has a permanent effect. Two methods can be distinguished. The first is selecting an embryo for having or lacking a specific gene that codes for a specific disease or property. This can be done by pre-implantation genetic diagnosis or PGD. The second method is human germ line engineering. Human germ line genetic modification (HGGM) promises to alter the reproductive cells as well, so that the engineered DNA becomes a permanent part of the genetic legacy. Thus, this form of genetic intervention represents an extreme case of human enhancement, for it would irreversibly interfere in human bodies. In public debates on these types of genetic interventions the term ‘designer baby’ pops up frequently. A term that was coined in the media only a decade ago.

In 1998, Dr. French Anderson in the United States asked for permission to try gene therapy on fetuses suffering from a condition called adenosine deaminase deficiency (ADA), a fatal childhood disease. The technique was likely to modify the developing germ cells of the fetuses, so it was a step further than gene therapy. Some media recognised the significance of Anderson’s proposal. Shortly after, both *Newsweek* (November 9, 1998) and *Time Magazine* (January 11, 1999) released articles titled ‘designer babies’, suggesting that the design of human beings according to our cultural preferences is within reach. Although Anderson’s plan to insert new genes into babies in the womb has never been practiced, so far, other types of designer babies seem to be alive and kicking. At least in the language

of the newspapers, typical uses of PGD are named 'designer babies', for the method allows for controlling genetic properties of an embryo.

The dream and nightmare of the "Perfect Child", however, is not a recent one. It is at least as old as the tale of the Monster of Frankenstein – to make a human in the lab and be in control over his traits, breaking away from destiny and the roulette of biological evolution. This cultural dream is renewed time over time. Darwinism and Mendel's hereditary laws inspired the eugenics movement at the end of the 19<sup>th</sup> century. Nowadays modern life sciences fuel the dream. In the 80's the test tube child was identified with this dream of the perfect child (Kalden & Beker 1993) and in the 90s the human clone. Over the last years, the genetically enhanced embryo, produced by PGD, gene therapy or by germ line engineering, took over the role of the true appearance of the 'perfect child'.

### IVF, PGD and HGGM

Amongst the technologies constitutive for both PGD and germline engineering, In Vitro Fertilisation (IVF) is by far the most important, for both technologies can only be applied in combination with IVF. IVF is indeed considered to be "the core technology upon which all of these new and controversial reproductive and genetic technologies are based" (Throsby 2004). IVF was recognised by bio-ethicists as the first technology transgressing the traditional goals of medicine, exchanging the treatment of diseases and the cure of medical conditions for a treatment of desires. Thus they opened the road for a medicine 'by desire' (Hellegers & Mc Cormick 1978).

IVF, PGD, and HGGM are being developed in medical practice and under the regime of medical regulations. An important driving force behind developing these techniques results from doctors and scientists emphasising its use for medical problems, for example to prevent the birth of severely handicapped children due to inheritance. The peculiar mechanism here is that the development of medical possibilities goes hand in hand with an extension of medical needs, the typical pattern of medicalisation.

IVF was no exception on this pattern. Traditionally infertility was not seen as a sign of a lack of health. The shift from being mainly defined as a social problem to being a medical problem took place in discussions on IVF in the 1980s. The distinction between social and medical problems was relevant (and finally blurred) in the political debate on the admittance of IVF. With a positive decision in the 1980s, the conceptual shift of infertility from a social problem to a medical problem was underlined by law.

PGD was first introduced in the United Kingdom in 1989. It was presented as a diagnostic technique in medicine that in some cases was a desirable alternative for the existing practice of prenatal diagnostics (PND). With PND an embryo is screened in its mother's womb for monogenetic diseases such as Huntington or cystic fibrosis. PND however is necessarily linked with the undesirable option for an abortion: In case a deviation is found in the embryo, the parents have to choose whether to abort the embryo or not. PGD enables to avoid this choice, because the screening and selection of the embryo takes place outside the womb. Meanwhile PGD is connected with the burden of an IVF treatment. So both techniques have a burdensome disadvantage: either a necessary IVF or a possible abortion.

Since about 2000, PGD has developed into a common practice within Europe and the US, its demand expanding little by little. In principle, diagnosis can be done on more than thousand monogenetic traits, but there are only a dozen genetic properties on which are tested (Baruch et al. 2004). Users travel within Europe for PGD, mostly for legal and

financial reasons but also because of non-availability of the test at home. Receiving countries are Spain, Belgium and the Czech Republic, treating parents that come from other European countries.

Germline engineering (HGGM) on the contrary is widely regarded as a no-go area. HGGM aims at modifying all of the cells in the body by changing one or more genes. To do so, the genetic modification must be introduced into the eggs and sperm, or very soon after fertilisation in a very early embryo. Formidable technical obstacles are there to be taken, before experiments will deliver hopeful success rates and before safety risks for human babies will be below social standards (Baruch et al. 2005). However, HGGM on monogenetic properties is technically possible in animals (Baruch et al. 2005). Animal germline experiments in fact have become fairly common: there are multiple examples of genetic engineers injecting (human) genes into the stem cells of mice, sheep, cows and other animals that are genetically altered by germline interventions (cf. Ter Gast 2007).

Policy makers and researchers share strong reservations against HGGM, mainly because of its consequence of changing the genetic heritage and its assumed risks for the child resulting from the procedure. As a result, it is subject to a worldwide ban. In many countries such as the Netherlands, parties keep themselves to a moratorium on germline genetic research on humans since 1998. The moratorium is a voluntary arrangement. Recently, however, on May 19, 2008, the British House of Commons accepted a law that allows the creation of genetically modified embryo's for research purposes. Implantation in the mother's womb is still prohibited. Thus designer babies created by germ line engineering do not exist yet.

### Existing designer babies

Nevertheless, some other designer-type-like babies are very much alive. They are selected by PGD for their genetic make-up, thus sorting a permanent effect on the genetic legacy. We will describe some examples of existing designer babies: the savior baby, the cosmetic baby, and the disability baby.

#### *The savior baby*

In 2000, at August 29, the first 'designer baby' was born in Colorado (USA)<sup>6</sup>. Adam Nash was procreated to save his sister Molly who suffered from Fanconi anemia, a deadly genetic disease that often leads to leukemia. Adam was conceived by IVF in combination with pre-implantation genetic diagnosis (PGD). Besides a technique was used, which identifies suitable donors for stem cell transplants. Stem cells extracted from his umbilical cord blood provided a perfect match for his sister's transplant. Adam is a so-called *savior baby*, a baby that is not only procreated for its own sake, but also for that of a severely ill sibling in order to treat him or her with gene therapy. Since Adam, many more *savior babies* have been born. This form of PGD is allowed in many countries nowadays. Savior babies however are a source of concern as well: what will for example be the psychological effect on a person, knowing that he or she was chosen because of certain genetic properties? Or, what is the effect on the saved sibling and its relation to his or her savior sibling?

#### *The cosmetic baby*

PGD can be used to select embryos that lack a certain monogenetic disorder of their parents. Sometimes such a disorder can be life-threatening. But there also examples of which the disorder is not even seen as a sickness, like being cross-eyed. In 2007 the Bridge Clinic in London has been granted a license to treat a couple who wanted to prevent

<sup>6</sup> See for example <http://www.guardian.co.uk/science/2000/oct/04/genetics.internationalnews>



their child inheriting a severe genetic squint. So here we meet, as *Times* (April 26, 2007) frames it, the ‘cosmetic’ designer baby. Mr. Grudzinkas, director of the clinic, commented that the use of embryos screening for cosmetic conditions such as squint will increase in the near future. He thinks the admissibility of these interventions is dependent on the level of family distress, which should be assessed by a physician.

#### *The disability baby*

Interestingly PGD can also be used to purposely select certain preferred ‘defect’. This type of designer baby is paraphrased ironically the ‘disability baby’ or ‘deformer baby’. The embryo of a disability baby is chosen for a specific, monogenetic characteristic that in daily life is perceived as an undesirable deviation by most people, such as deafness or dwarfism. A deaf lesbian couple Sharon Duchesneau and Candace McCullough – both deaf at birth – wanted a deaf child (cf. Barclay 2002). A number of sperm banks, however, turned down their request for a congenitally deaf donor. Eventually, they asked a male deaf gentleman friend, who had five generations of deafness in the family, to be a sperm donor. The baby Gauvin McCullough was born in 2002 and was almost perfect – he had slight hearing in one ear. In this case the baby was not conceived with the use of PGD. However, a few clinics in America and the UK provide the costly procedure to help disabled parents create ‘disabled’ progeny by PGD. Only a handful of these cases are reported. One of these is the attempt to select a dwarf baby by two dwarf parents.

The disability baby option causes sharp reactions by the public and by bioethicists. Critics call it “the deliberate crippling of children” (Saletan 2006a). The parents however appeal to their unwritten right to have a child that resembles them. “You cannot tell me that I cannot have a child who’s going to look like me,” Cara Reynolds, a dwarf mother said (Geller 2006). Reynolds started a PGD procedure to have a dwarf baby, but stopped it because her age limited her chances, and the insurance company didn’t cover the costs of the ‘treatment’.

#### Designer babies of the future

Influential radical geneticists, such as Gregory Stock (1999, 2002), Lee Silver (1997) and James Watson (Stock 1998), are convinced that within a few decades, genetic interventions in the embryo will increase resistance to diseases, optimise height and weight, limit aggression and boost intelligence. Even attractive traits of other species could become within reach: some geneticists predict children with the “night vision from an owl” and “supersensitive hearing cloned from a dog” (Darnovsky 2001). Stock (1999) states in sweeping words that: “Genetic enhancement technology promises [...] eventually to transform our very beings as ever more significant genetic changes are introduced into our genomes. This technology will force us to re-examine even the very notion of what it means to be human [as] we become subject to the same process of conscious design that has so dramatically altered the world around us.”

Many geneticists put aside such predictions as sheer fantasy. They contest his outdated paradigm of genetic determinism that assumes that desirable capacities such as intelligence or a healthy immune system are a direct result of our genetic make-up. This paradigm has rapidly lost its attraction after the Human Genome Project was finished in 2000 and has been replaced by the multi-factorial approach. In this new scientific paradigm of complexity most human properties and diseases are seen as the outcome of a complex interplay of countless genes and their environment. This insight puts a huge obstacle to the realisation of any dream on breeding designer babies by genetic enhancement. Controlling the complex interaction of multiple genes and environment to produce traits such as ‘intelligence’ or ‘eternal youth’ will be far more difficult than



changing a single gene. Moreover there exists very little knowledge about genes that concern positive traits, such as intelligence. The research done by Dr. Plomin (1998) on the genetic causes of high intelligence provides a scarce exception to this rule.

### Main social concerns on PGD

Few current medical subjects are as much discussed by ethicists and policy makers as PGD. Though PGD rapidly has become an established technology and a standard medical procedure in developed countries, it is still surrounded by manifold perspectives and concerns on its actual use and its future impact for individuals and society. On the extremes of the spectre, we find transhumanist and cultural critics - bio-conservatives as well as religious conservatives. Both consider PGD as a technology with potentially radical impacts for the human condition, either in a desirable direction, or in a threatening direction.

Transhumanists, like Gregory Stock, argue that PGD and germ line therapy will further enable us to control our fate and to diminish diseases. Proponents of a post-human future embrace these technologies, amongst other things, for broadening our freedom of choice, particularly the freedom of parents to have their offspring according to their own preferences. The unbridled confidence and enthusiasm of the proponents triggers the skeptics to turn the message upside down. Cultural critics have a range of concerns, varying from the fear for a culture of conditional love for children, to the fear for playing God. The waving future of post-humanity is turned into the end of our common humanity, in the words of spokesmen such as Francis Fukuyama (2002) or Richard Hayes, who is the director of the Centre for Genetics and Society in America. And in *Enough*, the outspoken criticaster Bill Mc Kibben (2003) argues that "improving" humans through genetic engineering entails the risk of turning people into humanoid robots: "We will rob our descendants of freedom of choice and may even extinguish our own species". The dominant argumentation style for these culture critics here is that of the 'slippery slope': in making this step, next steps (radically enhancing humans, the actual designer baby) seem to be unavoidable. As another quote says: "PGD prevents hellish diseases. In those cases, you have to say yes. And once you start saying yes, it's hard to say no" (Saletan 2006b).

These utopian end dystopian voices however are not the dominant voices in the current public debate surrounding PGD. In an analysis of newspaper articles between 2000 and 2004, Swierstra (2004) concludes that the overall tone was moderate and that utopian and dystopian overtones were largely absent during this period. Some researchers and practitioners declare that there is nothing new under the sun and PGD is business as usual. For example, Franklin (2006) sees PGD as just a logical variation on IVF. As a consequence, she believes that PGD's social consequences are not really different from those of IVF technology. Indeed a familiar concern is the increasing costs of healthcare and the equal (financial) accessibility for parents. PGD, however, also seems to disclose some new moral issues, like the returning question of the moral status of the pre-implanted embryo and on how the rest-embryos should be dealt with. A new question is also: to what purposes should PGD be limited - only in case of serious health problems or also for enhancing desired traits? Should society allow selecting embryos lacking a gene that codes for obesity, or squint, or dyslexia?

One of the recent controversies on the indication limits for PGD is on familiar breast cancer. In the UK, Australia, and the US, PGD for embryos of women bearing a genetic mutation of the 'breast cancer gene' BRCA 1 or 2 is a current treatment. In other countries policy makers refuse to widen the indication for PGD. Their argument is that in this case PGD is

not preventing a severe and lethal disease that will certainly appear. Instead there is an average life expectation of about fifty years, and there is 'only' a heightened risk for the bearer of the gene to get breast cancer. Does this warrant selecting and discarding embryos? (Green 2008)

There is also concern about long-term societal effects, such as the commodification of the child by way of these techniques, and the future implications for society caused by the assumed shift from genetics becoming a choice instead of a chance. Will a handicap be seen as an individual choice in the future, and thus lead to a loss of solidarity with the weak and handicapped? Some even believe that in the very long-term mankind will be genetically divided. For example, Lee Silver (1997) predicts a division of the world into a genetically enhanced elite ("GenRich"), and genetically deprived proletarians (so-called "Naturals"), in three hundred years time.

### Regulatory arrangements on PGD

In many countries, institutions and laws have risen to regulate reproductive technologies, such as IVF and PGD. PGD usually is permitted within legal restrictions. In an overview study, the Technology Assessment Bureau (TAB) of the German *Bundestag* concludes that in all the countries under study - Belgium, Denmark, France, Great Britain, Italy, Norway, and the USA - political discussions took place on the legitimacy of PGD and the limits of the indications for its use. These discussions resulted in divergent political regulations (TAB 2004).

In particular, the United Kingdom, seems to excel in public debate and regulation (Franklin 2006). In the UK, the birth of the first IVF child in 1978 encouraged a long-term deliberation on regulation. Twelve years later, this resulted in the Human Fertilisation and Embryology Act. According to Franklin (2006: 92): "The Act remains the most extensive, substantial and detailed legal framework ever created to regulate and govern what had previously been the legally uncharted territory of 'human fertilisation and embryology.'" Britain's formal agency, the Human Fertilisation and Embryology Authority (HFEA), must approve all requests for PGD.

At EU level, the most significant legislation affecting the use of PGD is the Human Tissue and Cells Directive which introduces a wide range of quality and safety requirements that clinics have to implement (TAB 2004). In the Netherlands, PGD is permitted within strict limits: only when a severe, untreatable disease can be prevented, for which there is no alternative approach. Severe restrictions are put on the practice of 'savior babies' such as the absence of alternative therapies and the absence of a donor. But also in the Netherlands there is ongoing debate about gradually stretching the practice of PGD. Currently there is much debate about whether to allow PGD for preventing BRCA1 and BRCA2 types of cancer-related genes (Staatssecretaris VWS 2006; De Volkskrant May 27, 2008). In America, however, still more PGD tests are offered, such as for preventing hemophilia gene or the cancer-related genes such as TP53.

It can be concluded that existing restrictions and regulations are subject to continuous discussion, and that in the near future no final social closure on the uses of PGD is nearing. The German TAB (2004) sees this tendency as disquieting: "It appears that without strong juridical or other regulative barriers, the praxis of PGD will be quickly extended shortly after its introduction". An important driving force for this is the use of PGD to optimise the results of IVF treatments, in order to select the most vital embryos for a higher success rate. This kind of use is not steered by a medical necessity like an indication for a genetic disease.

The examples of savior, cosmetic and disability babies form another sign of the widening tendency of PGD practice beyond a strict medical use for treating severe, life endangering diseases. Here we, however, see a surprising application of PGD. Whilst dystopian critics of genetic enhancement fear a child on recipe, the same technique here is used in an opposite direction: to reproduce properties that are usually perceived as a disabling and undesirable trait. But here they represent a mark of cultural identity. This might give a clue for a further direction in applications of PGD.

### Conclusion

As a consequence of the policy regulations created in the wake of IVF, European institutions seem to be fairly equipped to serve policy issues on PGD, such as efficiency and safety issues of the persons involved in PGD treatment. Issues of informed consent and family relationships get attention as well. Other typical concerns on the long term impacts for society, such as the fear for a 'commodification' of children, might be harder to address within current regulative arrangements.

Remarkably, the current regulative dynamics is characterised by a persistent pressure on widening the indications for PGD. Current laws even seem to trigger this tendency; for every formulation of a limit remains arbitrary to some extent, challenging groups to debate it. This happened in the case of the breast cancer gene in the Netherlands, where patient organisations successfully assailed the restrictive measures. This adds to a process of medicalisation. With IVF infertility was changed from a social to a medical problem. In this case the parents became patients. With PGD the focus has shifted towards the embryo; the next generation, and the type of genetic disorders that parents want to prevent their children from having. Here the moral entry point of the debate and ensuing laws was to strictly limit the use of PGD to the prevention of severe diseases. The ongoing discovery of monogenetic disorders, however, unleashes a constant political struggle about where to draw the next line. The closure of this process of medicalisation of negative genetic traits is not yet in view. As long as that is the case, there won't be closure on the fears and hopes for a designer baby either.

## 5. The need to study and debate liberal bio-politics

The development of enhancement technologies is depicted as a process out of control, because it is a development which takes place unnoticed, under the radar so to speak (cf. McKibben 2003, Habermas 2003). Within this out-of-control view the incremental development of enhancement technologies would make us blind for its revolutionary potential to change our very nature. Moreover, society's blindness for the long-term effects of these rapidly developing technologies and accompanying social practices would make it difficult to guide this development in a proper, democratic way.

Our essay shows that the above argument is both right and wrong. The cases illustrate that technology and science are not racing ahead of society, but guided by social debate and regulation. Regulation, however, is mainly focused on preventing the individual from risks and harm and on setting (moral) boundaries related to existing technologies. Far less attention is given to possible long-term impacts. Following the step-by-step development of science and technology, the policies that guide them develop incrementally. Human enhancement requires, however, a more moral and encompassing debate.

Section 3 positioned the current human enhancement debate in the tradition of eugenics. Whereas state-led (authoritarian) eugenics characterised old bio-politics, the debate on human enhancement is central to modern bio-politics. As Staman et al. (2008) analyse: "This time it is not the state, but we ourselves that transform the norms we want to live by. Through imitation, cultural acceptance, socialisation and group force we are setting new societal standards. The new bio-politics works bottom-up." The new bio-politics thus has a liberal touch to it, and is supposedly guided by individual freedom and choice. There is a growing realisation that bio-politics is a new political dimension (cf. Hughes 2004). It is crucial, therefore, to gain a better understanding of how human enhancement in a liberal political context is challenging mankind. Exploring the various facets of modern liberal bio-politics should, therefore, have a prominent place on the public and research agenda of our society. In this final section, we will - enabled and constrained by the content of our essay - deliver some elements for such an exploration.

We want to highlight the following broad themes as relevant areas for further research and public debate on human enhancement:

- The role of science and technology and the future expectations that surround them, including the question whether human enhancement research should be legitimised, and if so, how to conduct such research in an ethically sound way;
- The shaping of human enhancement in a variety of social practices, by a diverse group of actors, and the question of how to regulate this development;
- The meaning of enhancement technologies for shaping and perceiving ourselves;
- The need for developing socio-technical scenarios to think about possible ways in which human enhancement could develop;
- The hypothesis that the upcoming debate on human enhancement presents a new political dimension and that this bio-politics challenges mankind in similar ways as the ecological crisis does.

## 5.1. Science, technology and fiction for human enhancement

### Realistic estimations and spectacular expectations

Spectacular visions on potential future technologies drive the human enhancement debate. Accordingly, there is need for realistic estimations of the speed and direction of scientific and technological progress in this area. As neuroscientist Hagoort (2008) warns for: “Do not forget that a large amount of science fiction is told about how easy the brain might be afflicted. Fantasy often runs away with fact. Realistic results of cognitive enhancement through technological interventions in the brain are still very modest.” The cases in section 2 proof this point to be well taken. Many scientists themselves, however, are not averse to predicting spectacular technological possibilities in the decades to come. Look for example, at the NSF workshop on NBIC convergence (Roco & Bainbridge 2002). It is important, therefore, to also look carefully at the future expectations of scientists and engineers.

### The reality of dreams

In addition attention should be paid to science fiction, the realm of technological dreaming. While science fiction – often in combination with social fiction - may never become real science in a real world, it historically has had a strong impact on the world and the human condition. Section 3 gave a broad overview of the “dreams” that shape the Enlightenment project. The object of assessment must, therefore, be not existing science and technology alone, but also the relationship between science and imagination. In particular Dupuis (2007: 243) makes a strong plea for taking such an approach with respect to NBIC convergence: “Because, for the most part, the technologies in question do not yet exist in material reality. But in the form of “dreams” – with all their metaphysical, ideological, and popular and other dimensions – they are already there”. The case on pre-implantation genetic diagnosis and the concomitant theme of the designer baby illustrates Dupuis’ argument nicely.

### Human enhancement research

In *Radical Evolution*, the journalist Garreau (2006: 44) asks a military researcher, whether in order to save his daughter with cerebral palsy; he was willing to fundamentally alter human nature? His answer was: “Fundamentally altering human nature would be an unintended consequence.” The (ill) legitimacy of science for enhancement is another relevant theme that requires study and debate. Both cases on Ritalin and Deep Brain Stimulation showed that the enhancing effect of these technologies in healthy subjects is a serendipitous unintended outcome. What does the fact that science for treatment, although indirectly, leads to human enhancement technologies mean for the legitimacy of such research?

The NSF-workshop put the sensitive political question on the table whether science for enhancement is legitimate, and under what kind of conditions. Bostrom (2008) holds that science for enhancement purposes requires “- in addition to funding – a change of the paradigm according to which medicine is only about restoring, but not enhancing; and a concomitant change in the regulatory framework for medical trials and drug approval.” The case on (gene) doping in competitive sports illustrated that whether or not enhancement research is morally permissible, research that could lead to enhancement is already happening. King and Robeson (2007) claim that “only a few scholars have begun to address the problem of designing and conducting ethically sound research on enhancements, and have highlighted the difficulty of doing so”. Questions surrounding enhancement science, therefore, are still largely unexplored.

## 5.2. Human enhancement practices

Human enhancement is shaped in different social practices and domains. Its development will go hand in hand with the coming-into-being of 'new-collectives', new groups of people that share a common goal. These can be athletes claiming their right to use gene therapy to restore from their injuries, or mothers that have a breast cancer gene, and who want to use PGD to rule out the possibility that their daughters will inherit such a gene. Staman et al. (2008) point at the importance of identifying and studying the desires and activities of these groups in order to "see what new practices come up and what specific questions they pose, so that they might give us a clue about the future discussion of human enhancement and where that discussion will take place." Our short case studies were meant to give us some insight into the way human enhancement practices get constructed. Some interesting research themes can be distilled from them.

### Regulated systems under pressure

In the four cases that were described there was neither lack of regulation, nor lack of debate. Regulation, however, was bounded to a certain limited social practice. For example, the World Anti-Doping Agency has a policy in place against the use of gene doping in sports, and the use of Ritalin within the medical domain is guided by the diagnosis of ADHD. There is often much debate, however, about the efficacy of the regulation within these relatively confined domains. People shop for PGD across the borders, no test to detect gene doping is yet available, and also the diagnosis of ADHD is seen as rather ambiguous. Moreover, these regulated systems are constantly challenged to stretch their moral boundaries. For example, gene doping was forbidden, but at the same time the issue was raised whether gene therapy could be used in case of severe injuries. Interestingly, here two domains – professional sports and medicines – overlap.

In the medical domain, Ritalin, IVF and PGD all illustrate a trend towards medicalisation and "pathologisation" of an increasing range of conditions that were previously regarded as part of the normal human spectrum. In the case of PGD we saw a persistent pressure on the system to widen the indications for PGD. The rationale of this political game is to define a previously normal condition as in need for therapy. Others would say: to redefine enhancement as a kind of therapy. Proponents of human enhancement regard this as a "failure of the current medical regulatory framework to recognise the legitimacy of enhancement medicine" (Bostrom 2008). Bostrom (2008) recommends expanding the current "disease-focused" regulatory framework into a "health- or wellbeing-focused" framework, with for example, "enhancement licences" to ensure informed consent and enable monitoring of risks. Whether one agrees or not with such proposals, the way human enhancement challenges current regulatory systems presents an important field of research.

### Regulatory wastelands

Our cases also showed that outside the confined regulated domains regulatory wastelands exist. Ritalin is used outside the medical domain uncontrolled. While professional athletes will in the future be tested on whether they use gene doping, amateur athletes can use such doping, in principle, unattended. WADA will namely not be able to monitor all amateur athletes. It is important to study the political and cultural significance of such 'wild practices', and find strategies to deal with them. In particular, the interaction or borderline between the confined regulated spaces and the vast open and unregulated areas is in need of scrutiny. In the case of gene doping we sketched four possible scenarios in section 4.3.



With respect to Ritalin, its broad availability has led to an illegal market for its enhancement and recreational use. How to deal with this? Should we fiercely fight this illegal use, legalise it, or tolerate it, and, if so, to what extent? What are the long-term effects of these various strategies, whether repressive – like, for example the war on drugs – or tolerant? To value these unregulated practices, it is important to realise that a lot of new developments start off unregulated. IVF is a point in case. Regulatory wastelands, therefore, might also function as social experiments and / or playing grounds for new types of emancipatory movements.

### 5.3. The shaping of the self

Individualism forms the foundation of our liberal democratic societies. Taylor (1991) argues that we are living in a *culture of authenticity*, in which the major value in life is self-fulfilment. The moral idea behind self-fulfilment is that of being true to oneself, i.e. of self-realisation. Liberal bio-politics fits perfectly into this culture of self-fulfilment. Namely, it is individual free choice that should determine what constitutes human enhancement. Moreover, it is up to the individual to choose how he will employ human enhancement technologies for realising himself. As a consequence, studying the meaning of enhancement technologies for shaping and perceiving ourselves is topical.

#### The psychology of human enhancement

Our cases revealed only a few elements of this vast field of research. We saw boys using ADHD to become 'normal', but also to get high or more concentrated. We saw a deaf lesbian couple who wanted and got a deaf child. Besides the perfect 'disability baby', we saw the 'savior baby', which was selected by means of PGD for saving a sibling. This raised the issue of whether PGD was treating embryos and life itself as a commodity, but also the question of who's self-realisation should be central; those of the parents, the sibling, or the 'savior baby'. Is this baby respected for his donor qualities or for being human? To put it slightly different: will his life be fully affirmed? Life affirmation, or the lack of it, plays an important role in the discussion on human enhancement. For example, Hurst (2006: 117) fears that the genetics is leading towards "a medical model of disability, seeing disabled people as solely consisting of their impairments – not their intrinsic humanity". But human enhancement technologies may make all kind of people dissatisfied with what they are, and generate further desire to enhance themselves, trait by trait (cf. Tomasini 2008).

#### Self-realisation under social pressure

Of course, there is no such thing as self-realisation untouched by society. The individual is exposed to various forces, like the mass media, the market, public opinion, and science and technology. For example, Hurst (2006: 117) believes that "Modern culture fosters a climate of physical imperfection". Aitkenhead (2006) points at the important role the media has played in making cosmetic surgery socially acceptable. In the case of Ritalin, the role of the industry was criticised. Moreover, the issue was raised whether the medicalisation of ADHD, did not lead to disregarding the social issues involved. And finally, with regards to gene doping we mentioned the role economical interests play in professional sports, but also asked ourselves whether the public would really put down their TVs out of moral rejection for the use of doping in sports. To conclude, research is needed into the way these societal forces influence people's decisions with regards to enhancement technologies and the way they shape their lives.



#### 5.4. Images of the future

##### Long-term effects

As described in section 2, modern liberal bio-politics is guided by utopian and dystopian views. Our cases show that such future images, like the designer baby (PGD case) and the “pill for every ill” (Ritalin case) play an important role in the public debate. They steer up the discussion, because they represent the moral sources of the ethical debate. Policy makers, however, find it hard to give a proper place to “speculations” about future technological possibilities and long-term social impacts. Instead, regulation develops case by case, incrementally from one new technology to the other. This creates a kind of existentialist uncertainty with our modern democracies, because our common experience is that of ongoing scientific and technological developments. By jumping from technology to technology don't we waste the possibility to reflect on the long-term development of science and technology and guide them in a more democratic manner? It is important to study the way in which possible long-term impacts are currently dealt with in regulatory processes and look for ways in which future moral reflexivity within policy making and the political debate might be strengthened.

##### The need for socio-technical scenarios

The horrific experience of the Holocaust proves the need for taking such a broader outlook. For this we need socio-technical scenarios. Many current scenarios are still related to the model of authoritarian bio-politics. These scenarios stay relevant for looking at the future. If only, because the world is still full of authoritarian regimes. But we need to complement them with scenarios that fit liberal bio-politics. Such an outlook could lead to all kinds of surprising and, therefore, politically and ethically inspiring scenarios. The “disability baby” presents an interesting scenario, but also the insight that professional knowledge workers use Ritalin to higher their concentration adds a new dimension to the debate on Ritalin. Starting from a liberal bio-political context, we should be able to make educated guesses on how human enhancement may become embedded in our society. In this respect, there is surely a role to play for the arts to stimulate the moral and political debate on human enhancement (cf. Ter Gast 2007).

#### 5.5. Do the dots of human enhancement connect to a wave?

According to the historian Bess (2008) the magnitude of the human enhancement matter is of the same order as that of the environmental crisis. This interesting parallel can be explained further by means of Toffler's (1980) metaphor of revolutionary waves. The agricultural revolution presents the *First Wave*. This started some ten thousand years ago and represented a slow wave of change. Some 350 years ago Bacon's dream inspired the start of the Second Wave: the industrial revolution in Western societies. The *Second Wave* of change was faster. In Merelman's (1990) terminology this Second Wave was about ‘manipulating external nature’. Its main resources were natural resources, like steel and coals, et cetera. During the 19<sup>th</sup> century the industrial revolution introduced the still common Left-Right dimension into politics; with Marxism at one side of the spectrum and laissez-faire capitalism at the other end. The Second Wave also led to the rise of environmentalism and various green parties (cf. Jamison et al. 1990). In particular, after the 1960s sustainability has become an important political issue.





Now we are experiencing the *Third Wave*: the info-bio revolution. This gigantic wave of technological, social and cultural change started after the Second World War, and is since then changing our world at “hyper-speed” (Toffler 2000). As explained above, this Third Wave is about ‘manipulating our internal nature’; it is about mastering life and its resources are our bodies, minds and culture (Van Est 2008). The crucial question now becomes whether the information age brings with it a new type of politics. Many authors answer this question in a confirmative way: it is bio-politics (Rifkin 1998, 2001, Fukuyama 2002, Hughes 2004, Van Est et al. 2006).

### Human sustainability

It is important to further scrutinise this central modernisation hypothesis. Do the technological, cultural and political dots of human enhancement indeed connect to the Third Wave? To what extent can we learn from environmentalism? Are we in need, with respect to human enhancement, of a concept like *sustainability*, which despite of its fussiness, seems to guide the discourse about our external nature? Do we need a sustainability concept related to our internal nature, our bodies and our minds? Is there something like human sustainability? How do we safeguard such human sustainability, and who will do the pioneering work? If bio-politics is going to be a more and more important dimension of the politics of the 21<sup>st</sup> century, who will be the protagonists? Are we seeing the arrival of a bio-political movement; this time not a green movement, but a “red” one? Are the bioLuddist the frontrunners of such “internal nature conservatism”? Are the transhumanist libertarians, or signalling a modern social-democratic emancipatory movement? This short essay has hopefully illustrated the need to address, through study, debate and the arts, all these big and intriguing questions.

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