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The New Genomics Agenda

A Political Epilogue to the Book of Life: Update on Pharmaceutical Multinationals and the Human Genome

Issue: For five years now, public concern about genetic engineering has been riveted on GM crops and foods. But, advances in mapping the human genome have spawned new pharmaceutical industry opportunities. While the prospects for human cloning and stem cell therapies grab the headlines and divert our attention, the companies are pursuing more strategic agendas. Although the majority oppose reproductive cloning, public and policy opinion is "soft." Industry's latest and most lucrative market – Human Performance Enhancement drugs – "H*y*PEs" – are not even on the policy agenda. This issue of *ETC Group Communiqué* looks at the latest developments as well as who is going to be most affected.

Impact: Reproductive cloning will never be more than a niche market for the distressed and desperate. Similarly, "bio-bombs" targeting ethnic or racial communities – though plausible and despicable – will seldom outperform conventional weaponry. The big money (and risk) lies in human performance enhancement (H*y*PE) therapies and drugs that make it possible to control dissent and eradicate the "different." Enhancement assumes societal agreement on acceptable and unacceptable human qualities and characteristics and reduces all social responses to human difference to medical solutions. Of equal concern, HyPE technologies in military hands can become disabling technologies.

Fora: None. To date, the World Health Organization (WHO) has sidestepped these issues. WHO's Assembly has taken the tried and trite path of condemning reproductive cloning but it has failed to survey the whole horizon of new genomics technologies. In addition, the Convention on Biological Diversity (CBD) has failed to resolve the unfinished business arising from the Rio Earth Summit almost ten years ago and to address the political placement of human genetic diversity. Though UNESCO adopted a weak Declaration on the Human Genome and Human Rights in 1997, the document does not address serious issues such as intellectual property and is the wrong place for such an important document. The document should be transferred to the UN Human Rights Commission and developed into a legally binding convention.

Policy: A "slam-dunk" though it may seem, comprehensive cloning legislation is a litmus test for other genomics issues. If governments get this wrong, there is little hope for the rest. This said, the real battleground will form around H*y*PE therapies and drugs. It is time for the United Nations to really address the genomics agenda. Following debate at Rio+10 in South Africa in September 2002, the UN should hold a Special Session of the General Assembly on Genomics and Genetic Resources (human and other) in order to address unresolved issues and assign institutional responsibilities.

Context: "Crotch to cranium" genomics:

Bartending the human cocktail party politics

Scoping the terrain of human genomics issues is becoming more difficult day-by-day. As our scientific data on the human genome evolves, our understanding seems to decline. Here are some of the developments that are contributing to the confusion…

Cocktail: Until a few months ago, the scientific community told us that human beings were incredibly complex. Compared to other species with perhaps 30 or 40 thousand genes, we were purported to be carting around somewhere between 80 and 120 thousand different genes. Then, all of a sudden, we were knocked back down to a gene count no more impressive than yeast or fruit flies. Not only are one-quarter of our genes identical to those found in yeast,[1] but of the 289 "disease" genes found in our DNA so far, 177 of them can also be spliced out of the DNA of a fruit fly.[2] According to Robert May, the UK's chief scientist, *homo sapiens* shares half its genes with a banana. And at the announcement of '*The Book of Life*,' American scientists surmised that we share half our genes with the roundworm. This doesn't leave "humanity" much room to maneuver. The human cocktail, we might conclude, is one part banana, one part roundworm, with a twist of lemming?

Recipe: The recipe of life has undergone several major adjustments in the last couple of years. The sequence of genes that pattern the cellular development of the human form is almost a carbon copy of sequences that pattern the formation of fish and ferns. The genetic complex that forms eyes in a fruit fly forms human eyes as well. Nature, it appears, uses a few basic building blocks in very different ways as a template for constructing all of biological diversity. In manipulating the human genome and determining the ownership and control of genes and sequences, we may be making decisions that touch upon much more of the living world than we assumed even a year ago. As such, it is unwise and illogical to separate issues surrounding plant genomics from those that surround human genomics.

Rusty Nail Genes: If profound implications arise from the genetic similarities *between* species, more may arise from the supposedly dormant genetic material *within* each species – so-called "Junk DNA." By some estimates, 97% of our genetic material is discarded "junk" – refuse from almost four billion years of evolution. We seem to throw away very little – confirming the views of some that our closest genetic relative could be pack rats. In the near future, most genetic manipulation of crops, livestock, and humans may be drawn not from transgenics but from intra-genetics. "Intragenics" involves the increasingly feasible task of simply digging into our genetic basements and attics to turn on dormant genes – reactivating old traits that may have served some function in our evolutionary past. With new possibilities unfolding it becomes clear that much of the political debate over "transgenic" species manipulation may have been founded upon a sense of genetic 'integrity' that is not borne out in reality. But, the growing capacity to summon discarded DNA from the trash heap may render the direct (but not necessarily indirect) use of foreign genes unnecessary. Suddenly the political debate looks different.

Blender Effect: The final lesson of recent times is that the technology-divide between genomics, neural sciences, material sciences, informatics, etc. is becoming less and less relevant. It is the combination of technological developments across fields that make the pace of change – and its direction – alarming and uncertain. In short, the pace and magnitude of technological advances is making it clear that we should proceed carefully as we draw political lines in the shifting sands of science.

Party: The genomics debate is, in the end, a political debate. Far from diminishing the importance of the issue, this is as it should be. A series of industry initiatives – lower in profile than cloning – run the gamut from

human reproduction to neural manipulations – from crotch to cranium. Of particular concern are the new Human Performance Enhancement (HyPE) drugs and therapies aimed at improving the performance of individuals in all areas of life. What are the political concerns? Where should concerned activists position themselves in the coming debate? Policy-makers and social activists need not be mesmerized by genomics technologies. The old analytical matrix for determining priorities remains true. The essential questions include:

- What offers the greatest control?
- Where is the profit-potential highest?
- What are the major socio-economic and environmental risks?
- Who stands to gain the most?
- Who stands to lose the most?
    - the poor?
    - the disabled?
    - the different?
    - the reproducers?
    - the workers, warriors, and "won'ts" (dissenters)?

In the final analysis, it is most important to evaluate the impact of new genomics technologies on those who are vulnerable. In the quest to successfully develop new technologies, drugs and therapies and market them to consumers, a number of different agendas emerge. Communities of the different, including disabled peoples, indigenous peoples, social outcasts, women and those who hold opinions different from the norm are all targeted by the research. We will consider the implications of the different agendas at work.

Agenda #1
Targeting communities of the different: "Dis-ing" the different - germline therapy

Now that we have the *Book of Life*, the theory goes, we can give it a better ending. We can even change the plot. No more tragedies – just romance and adventure. Doctors will be able to get down and dirty with our DNA and clean up nature's little hiccups. Errant genes and proteins can be patched up and brought into line.

There are two ways to adjust our genes: by somatic gene therapy (any genetic change will affect only a single patient) and by germline therapy (reproductive cells are altered so that the change will be passed down from generation to generation). Most governments and scientists are understandably queasy about germline therapy since any genetic change has the potential, over time, to reshape humanity. Somatic gene therapy is often perceived to be much less dangerous since only one person is involved and the genetic adjustment cannot be passed on.

The big interest in germline therapy is to rid humanity of its genetically inherited diseases. Some of those who have the diseases aren't so sure they want to be got rid of. Support and disability groups are divided. Pharmaceutical companies are promoting some disability groups who make the public case for embryo research, stem cell research, and germline therapies. Many with the same disease argue that this too is diversity and fear that the eradication of our differences will lead to a new eugenics movement.

Proponents of purely medical or genetic solutions argue for the necessity of the research. The poster child for this view has the additional appeal of being an iconic 'superman.' Christopher Reeves – the actor who played Superman in a series of Hollywood movies and later suffered a spinal chord injury during a riding accident – provides powerful imagery in the fight to continue to make use of genetic engineering and stem cell technology (which uses cloned embryos) to find a cure. A commercial in which he starred used computer graphics to have him 'walk' in the future, outraging many in the disability movement.

There is a growing voice in the disability movement arguing that this genetic research and testing fosters a climate of intolerance towards people with disabilities.[3] It also

perpetuates the belief that disability is only a medical problem with the new genetics as the promised solution. Society has to confront disease and disability groups not as medical problems to be solved, but as biological realities. There must be a concerted effort not to disable these biological realities through socially constructed interpretations of disability.

As disability rights advocate Gary Presley wonders, who will be the poster boy for access? "The drum beating for cure, for the magic stem cell in a syringe, drowns out those of us who insist access and accommodation, the support of basic healthcare, and educational and professional opportunity is equally important."[4]

Agenda #2
Controlling reproduction technologies: Gender benders

Massacring mom: reproductive revolutions
In the 60s, the cutting edge technology was the one that let you have sex without having kids. In the 90s, the big technology was the one that let you have kids without having sex. In the ETC Century, neither parent may have much of a role.

As a result of the new technologies, women's reproductive role is increasingly being challenged. Promises of artificial wombs and other reproductive technologies abound in a debate where the ultimate suggestion is to remove women from the process altogether through reproductive cloning. *New Scientist* reported in late May 2001 that US researchers had developed a new 'chip' that has the ability to automate all stages of in vitro fertilization.[5] According to the report, the artificial reproductive tract will be able to sort and test embryos for genetic flaws. The researchers have applied for patent protection for their invention.

Non-apparent parents: Well-known geneticist R.C. Lewontin has argued that a human clone does not have a single genetic parent as most assume. A cloned child, he argues, is not the child of the person whose genes were "passed through" to the clone. Rather, the clone is simply another offspring of the donor's original parents.[6] In essence, people are just containers of their parents' genes. Given arguments like this, a legal case could be made to claim that reproduction is no longer something that a woman or even a couple can control since, when it comes to cloning, they are not the "parents" – therefore their consent is irrelevant.

Since the use of embryonic clones in research began, the issue of cloning has become linked to the abortion debate, especially in the US where feelings about this issue run particularly high. The pro-choice debate is anchored by the obligation to defend a woman's bodily integrity. But in cloning there is no such defense needed because a woman isn't pregnant yet. So objections to continuing the life of a clone on those grounds would be somewhat difficult. For the anti-choice camp, the argument is that if you had sex and got pregnant you should carry the child to term, but cloning originates in a test tube not a womb. So anti-choice groups condemn asexual reproduction as a moral offense. In other words, they insist, if you want a baby you must have sex.[7] Either way, arguments against cloning by both groups run amok in rhetoric out of touch with the new technological realities.

Agenda #3
Using indigenous and other ethnically distinct peoples

The publication of the *Book of Life* made it clear that humans share most of the same genes. But each person is also genetically unique, and in every person's DNA there are small differences that together determine genetic individuality. Over the past few years, scientists have developed greater capacity to understand the medical significance of these differences. It is believed that genetic diversity information will aid in the discovery of genes responsible for particular diseases and ultimately to new

diagnostics, drugs and therapies to treat genetically related diseases.

Even in the absence of actual drugs and therapies, the economic value of gene collection activities continues to be significant. In a controversial deal struck in early 1999, the government of Iceland sold the genetic heritage of its entire population to genomics company deCODE who, in turn, sold much of that data to Swiss pharmaceutical giant Hoffman LaRoche for US$200 million. In 2001, revenues for genomics company Celera doubled to close to US $90 million for selling access to its company's database and for biological analysis of the genome.[8]

Finding genes for disease and difference often involves vulnerable groups. Commercial gene hunters are particularly attracted to population groups that have been isolated for reasons of geography, culture, or politics because of their genetic homogeneity. These populations were often founded by a relatively small number of individuals and, having remained somewhat isolated, have less variety in their genetic make-up. In such a closely related population, it is more likely that the same genes cause a disease that runs in a family or community – a mutation that may have entered the family gene pool through a distant ancestor.[9]

The race to find these unique genes is so fierce that private, profit-driven commercial ventures, rather than intergovernmental institutions are setting the rules of negotiation and consent, and the terms for compensation. In the complete absence of intergovernmental oversight and regulation, a new wave of for-profit DNA collection ventures – many of them fly-by-night operations – are popping up in remote rural areas, on the Internet, and on Wall St. A sampling of some of the more recent examples include:

- the government of the tiny Baltic state of Estonia put the genes of its 1.4 million citizens up for sale with an initial investment of US$200 million without any public discussion;[10]
- the Government of Tonga in the Pacific purportedly sold the rights to its entire gene pool to an Australian biotech company, without the consent of the Tongan people;[11]
- the same Australian biotech company claims to have reached agreements to access the genetic information of specific populations in Mauritius, Nauru, and Tasmania;[12]
- families in the eastern Canadian province of Newfoundland are being recruited for their genetic material by a group of doctors collaborating with a UK genomics company;[13]
- a project in the UK is collecting DNA samples from half a million Britons despite criticism over the lack of public consultations and the poor allocation of health care resources;[14]
- companies are using the Internet to recruit large populations of genetic donors.[15] The goal of web based companies like DNA Sciences (www.dna.com) is to use the internet to recruit hundreds of thousands of volunteers to fill out health surveys and donate blood samples that could yield useful information. Their goal is to "establish a huge database about people" – in exchange for "nothing less than a chance to be part of history" – and nothing more;
- researchers connected to the Human Genome Diversity Project are releasing a new database housing hundreds of thousands of samples of 'unique' populations, despite intense criticism from indigenous and other civil society groups.[16]

No lifeguard at the Gene Pool: Most of the existing databases housing the genetic material of ethnic and vulnerable groups are privately owned and therefore not subject to ethical guidelines, or other regulations pertaining to the use of the material. The confusion and uncertainty surrounding the collection and regulation of human genetic material has led to further 'opportunities' for the private sector.

A new company, First Genetic Trust, is selling itself as a third party intermediary

between the providers of genetic information (i.e., people) and the users of genetic information (i.e., researchers and health care providers). In an effort to assure individuals that they will retain control over their own genetic information, First Genetic Trust promises to create a secure and independent "gene bank."[17] First Genetic Trust entered into a partnership with IBM Corporation, the largest information and technology company in the world, to put in place an "information technology infrastructure."

The theory is that genes will not only predict disease, but will also be used to predict individual responses to certain drugs. In order to get the right drugs to the right people doctors will need convenient access to genetic profiles. To avoid adverse drug effects, individuals will want to have their genetic information readily available. But because this information can be misused, the company promises to protect the material and ensure that it is kept safely from those who might use it improperly. How they will keep it safe has yet to be answered. For the foreseeable future, the company will make its money by selling access to the genetic information it collects to pharmaceutical companies.

In reality, individuals and groups have little or nothing to say over what becomes of their genetic information once it has been collected and stored in databases. Gene collection activities are taking place without a lifeguard to protect people and communities. To date, there has been no international response to set rules for regulating collection, access to and exchange of human genetic material. There is an inherent risk in allowing the private sector to exert heavy-handed control over, not only the collection and use of human DNA, but also its regulation.

Agenda #4
Playing with poor people: Cheap genes and poor replacements

The poor are always with us – in the lab

In examining the genetic databases listed above it would be hard not to notice that researchers can benefit from the easy availability of genes from the poor. Increasingly, the exploitative relationships inherent in these arrangements are being questioned. For example, researchers at Harvard University conducting a study funded by the pharmaceutical giant Millennium have been accused of exploiting the vulnerable position of the poorest Chinese.[18] At least 14 projects were undertaken in China, involving as many as 200 million Chinese citizens. The projects include research on obesity, schizophrenia, pulmonary disease, atherosclerosis, hypertension, and colon cancer.[19]

Mounting evidence indicates that the research subjects, located mostly in Anhui province, one of China's poorest provinces, were subjected to violations of rights and protection. In many cases, the research was conducted under conditions that made proper informed consent virtually impossible. The real health risks associated with some of the research studies were heightened by a health care system, particularly in the rural areas, that has completely broken down due to the changes in the Chinese economy.[20] According to many health workers and other observers, the blood supply is heavily contaminated and syringes and needles are not sterilized and are re-used.[21] In many cases, the research is being conducted in China specifically because the population does not have access to modern medicine and "China offers a low-cost research venue."[22] According to critics, the Harvard researchers are not ensuring that their research subjects are provided access to these therapeutic drugs – a situation that would not be tolerated in the North. In short, serious ethical questions arise when many of the studies will bring no benefits to the people being studied.

Pills for Poverty: Scientists and others are desperate to assure the world that their breakthroughs will benefit the poor. Last year a 'widely honored scientist' was quoted as defending germline engineering on the grounds that "poor families could engineer their children to be basketball players."[23] Yet, out of research to cure genetic disease, therapies to eliminate undesirable and add desirable genes will inevitably emerge. Germline genetic engineering is still illegal in most countries. But because the world is driven by market forces, it is unlikely to be long before the desire of parents to give their children (and their children's children) a little genetic advantage will be no more unusual than sending children to private schools. In May 2001, it was announced that 30 genetically altered babies had already been born in the US – a procedure that would be illegal in most countries.[24] Human genetic enhancement is a continuation of current and highly popular market trends such as cosmetic surgery and other medical methods of "improving" the human form. This genetic enhancement may not come in the form of controversial genetic procedures but from drug therapies. Ultimately, it will be the rich who will preferentially alter their children. The poor will be exploited for their genes, but they will be the least likely to benefit from potential breakthroughs.

Agenda #5
Managing dissent/marketing consent
Making the world $afe for $itizens

In addition to eradicating the different, some governments and industries would like to control (or eradicate) dissent. The means of 'controlling dissent' includes everything from the use of population-targeted genetic weapons to the bio-sensors necessary to detect specific populations, to the informatics and neural science technologies to make sure that the weapons finds their mark. In the meantime, researchers are finding other practical uses of these technologies.

IRA Irises: Engineers at IBM have developed a sensing technology called BlueEyes that uses video cameras and microphones to identify and observe actions of the user and extract key information.[25] BlueEyes interprets facial expression information and uses infrared light to determine the direction of the pupil and thereby extract information. The objective is to make computers with greater human abilities by giving them a 'sense of sight.' Airports like London's busy Heathrow have already promised to begin using 'iris scanners' in order to speed up passport control lines – and of course, to prevent undesirables from entering the country.[26] On their website, researchers at IBM claim other uses, including operating ordinary household devises, designing cars, or assisting teachers by indicating whether a student is bored or frustrated. However, some of the technologies more likely – and more insidious – commercial applications have already hit the streets.

In May 2001, *Technology Review* reported that a number of large retailers were using the BlueEyes technology to gather data on eye movement and facial expression to track customer preferences.[27] Retailers placed cameras in stores that trace the pupil movement of customers to determine how long they looked at in-store advertising and whether they registered interest in the product. IBM claims that its BlueEyes technology can infer user interest based on what it sees the user doing and can adjust advertising to suit the users 'needs.'[28] The American Civil Liberties Union has registered concern, noting that it won't be long before the technology will be able to identify people and their spending habits.

At MIT researchers working on the "Affective Computing project" have come up with a number of computer systems that, in one way or another, sense the users' emotional state. A CD player known as Orpheus uses a palm pilot that accepts physiological information and plays music based on the current mood of the listener and their preferences – whether, for example, you want to hear sad music when you are sad, or music to change your mood.[29] In the pipeline

are also wearable computers that sense bio-physiological changes that reflect changes in emotional state. Blood volume pressure earrings and skin conductivity sensors that are attached to rings and bracelets or inserted in shoes have already been developed.[30] A US Patent application published on May 17, 2001 describes a method by which objects can detect the user's state in a visual, tactile and auditory manner thereby establishing more natural communication between the user and the object.[31]

Finally, The Sunshine Project, a biowarfare watchdog organization, has released a report on "non-lethal weapons research in the US."[32] The report provides information on the US government's non-lethal weapons program to control armed enemies and civilians. Psychoactive substances whose effects range from inducing sleep to overpowering hallucinations, so-called "calmative agents," have been the subject of US research for civilian crowd control. In short, the same technologies being used by industry to improve performance may be used by the military as weapons of control.

Many of these technologies are still in their infancy. Though useful applications of these technologies may be possible, a more likely scenario is the misuse of the technology to control certain activities and influence people's buying and thinking habits in ways that push the limits of democracy and dissent.

Agenda #6
Human Performance Enhancement (HyPE)

The boys from Brazil – or the Boys from Basel?

Clone at Home 02: In the 1960's, author Ira Levin wrote *The Boys from Brazil* – a sci-fi thriller wherein mad Nazi scientists clone Adolf Hitler into the wombs of a couple of dozen surrogate women in Brazil. The cloning of the sheep, Dolly, in 1997 re-awakened society's fears and fascination with human cloning. Forty years ago the threat of human cloning – be it Hitler or Ghandi – seemed remote. In February, 2001, however, two infertility specialists in the USA and Italy proclaimed that more than 200 couples had come to them asking for help in achieving a cloned offspring and declared that they would give the world its first cloned human infant sometime in 2002.[33] By some estimates more than 300 medical centers in the US alone may have the technical capacity to achieve human cloning now. How many out there actively in the race for the first clone is uncertain but the betting is high that it is just a matter of months before the first child is born.

Many countries have banned cloning human infants. But cloning regular cells to make them into stem cells that can build body parts or cure disease is increasingly being accepted. Britain recently approved the creation of human embryos through cloning and their use to derive embryonic stem cells. US President George Bush, under pressure from anti-choice groups, has ended federal funding to any new embryonic stem cell research.[34] The ban, however, does not apply to privately funded US researchers who are free to continue work in the area. Bush has also permitted federally funded research to continue on approximately 64 cell lines that are reported to already exist.[35] How many stem cell lines actually exist is being hotly debated.

Many people are asking if this kind of cloning is the thin edge of the wedge that will help pry the door open to reproductive cloning. Human cloning acts as a kind of governance litmus test. Poorly constructed legislation could open the door to cloning in some countries. In other cases, countries have denounced cloning without enacting legislation – leaving their citizens with the assumption that cloning is illegal when it is not. Then, too, some countries have established "sunset" clauses to cloning laws that offer false comfort to its opponents and actually encourage proponents to believe that

– by the time the technology is reliable – the ban will have evaporated.

Is it the Boys from Brazil we need to fear or the Boys from Basel? The configuration of super pharmaceutical centers in Basel, Switzerland and downstream along the Rhine into Germany have other plans for us. Some biotech industry groups and individual companies are vocally opposing reproductive cloning, while actively pursuing embryo research. Most of the money is not going to be in cloning or, for the time being, in designing better babies. Currently, the only real money being made is in the genetic testing business, which already accounts for over $1 billion in revenues.[36]

The potential of the market in human performance enhancement drugs and therapies is something less than a revelation. Twenty-five years ago, the CEO of Merck (still one of the world's top drug companies) told *Fortune* magazine that he wanted to move his company toward making drugs for healthy people[37]. This makes perfect commercial sense. "Well" people are employable and can afford to pay for medicines. "Well" people live longer than "sick" people so they can buy medicines longer. "Well" people are never "cured" so they are free to keep on filling their prescriptions. "Sick" people either get "cured" (and thanklessly stop buying) or die. Worse insult, "sick" people attract political sympathy if drug prices are beyond their reach – not so with "well" people. The only new wrinkle since Merck's 1976-business plan is that with biotechnology "well" people can get even "better." As Tom McKillop, head of AstraZeneca, gleefully pronounced in July2001, "I say everyone should die healthy!"[38]

Historical cue – The Profit Addiction and the Research Affliction

The pharmaceutical industry's enthusiasm for designing drugs for well people actually has a long history. Morphine was purified from opium at the outset of the nineteenth century and first commercialized by Merck in Germany in 1827.[39] Bayer was a major and early proponent of amphetamines and brought the world two blockbuster commercial winners – aspirin and heroin.[40] In 1892, a Parke Davis (drug company) publication intended for doctors provided 240 pages of documentation extolling its two leading products - coca and cocaine. Only 3 of the 240 pages discussed the drugs' unfortunate side effects.[41] Following World War II, the industry routinely blended barbiturates with amphetamines for diet drugs in order to encourage consumers to stay on the regime (and keep buying).[42] Sandoz (now Novartis) invented LSD (though the company was horrified by its abuses).[43]

The industry's position on "recreational" drugs has always been ambiguous. Company lobbyists managed to delay the Convention on Psychotropic Substances 1971 – an international convention which introduced new controls over a number of synthetic drugs according to their abuse potential on the one hand and their therapeutic value on the other – extracting numerous governmental concessions in the process.[44] With the annual global pharmaceutical market in the range of $300 billion, the illicit narcotics market, valued at $400 billion in 1995,[45] is hugely inviting. New H*y*PE drugs could allow the industry to assert its position in this market by offering a battery of well-people products without the stigma society attaches to hard drugs like opium and cocaine or soft drugs like amphetamines and barbiturates.

Originally "ethical drugs" were defined as drugs advertised only to doctors and pharmacists, but not to potential patients.[46] Now that the industry is advertising on television in the US and elsewhere does it mean that there are no longer any ethical drugs or drug companies? For example, television has allowed Viagra to slip quietly from being a drug combating "erectile dysfunction" to an aphrodisiac.[47]

The industry's neglect of the ill is also well documented. Of the $70 billion expended globally on health research in 1998, barely $100 million was devoted to anti-malaria research. Of the 1223 drugs brought to market between 1975 and 1996, only 13 targeted tropical diseases and just four of these came from the private sector.[48] Private pharma's commitment to patients was underscored by a US Government Office of Technology Assessment (OTA) review in 1993 that showed that 97% of the 348 'ethical' drugs brought to market by the 25 leading US drug companies between 1981 and 1988 were 'me-too' copies of existing medications. That leaves only three percent that offer genuine therapeutic advances. Of that lowly three percent, however, 70% were the result of public research and more than half of the innovative new drugs proffered by the private sector had to be eventually removed from sale due to unanticipated side-effects. [49] Consider the waste of resources. Of the $70 billion spent globally on health research, approximately $39 billion comes from the private sector. If 97% of this sum is squandered on medically useless drug turf battles, then almost $38 billion is lost – a sum sufficient to address all or most of the South's primary health care needs. How does the industry get away with this? In September 2001, *The Wall Street Journal* reported on a meeting of the world's major medical journals. The meeting was called to address abuses in scientific reports of medical trials as presented in their publications. The journals concluded that corporate influence on peer-reviewed publications was rampant and unacceptable. Most surprisingly, an editorial in the *Journal of the American Medical Association* concluded that "the use of clinical trials" – always cited by industry as a huge research expense – is "primarily for marketing" and described the tactic as a threat to good research.[50] These are the enterprises to which we are entrusting The Book of Life.

All worked up about HyPE

Making "well" people "better" has significant benefits for employers. Try as we will, people are likely to remain the most versatile and efficient tool of production for many jobs for the foreseeable future. But we do have our defects. The pharmaceutical industry is working on developing "performance enhancement" drugs to turn workers into super humans when they should be developing drugs that would make their employers human. Employers waiting to use the new drugs, including the US government, are lining up at the pharma companies' doors. Some recent innovations that could help employers include:

- *8 Days a Week:* Cephalon Inc. has developed a drug called Provigil for the treatment of narcolepsy (a neurological disease that causes irrepressible sleep attacks throughout the day). Because Provigil is not an amphetamine, it is attracting attention as a possible alertness aid for healthy people. Cephalon confirmed it is discussing with the US Defense Department testing whether Provigil will help sleep-deprived soldiers stay alert longer.[51]
- *Rhythm and blues*: Last year Northwestern University researchers patented the gene responsible for the circadian rhythm.[52] The mammalian circadian clock is known to regulate 24 hour rhythms in most, if not all, physiological systems. The patent for the so-called "clock gene" covers not only uses of the gene for sleep related problems, but also jet-lag, alertness, "altering the mood state or performance," "altering the stress response in humans," diet and food intake, sexual function, enhancing mental and physical performance, improving the environment of intensive care facilities (a 'happy' drug), and many other uses. Since the patent issued, numerous drugs and therapies have subsequently been developed and patented.
- *Stringed out quartets:* A drug meant for congestive cardiac failure is best known as "the musicians underground drug" because of its effect on musical performance. The drug, known as beta-blockers, blocks the receptors for the

physical effects of a person's natural 'fight or flight' response to fear. A study in the late eighties indicated that 27% of symphony orchestra musicians were taking beta-blockers.[53] A patent issued in April 2001[54] describes the use of beta-blockers in mild anxiety disorders and suggests that FDA approval for non-heart related conditions might not be far off. If companies are able to market the drug for other purposes, chances are high that the market share will increase. A drug therapy capable of blocking fear responses would have significant work-related applications.

- *Company genes:* The Council for Responsible Genetics, an advocacy group in Massachusetts, has documented hundreds of cases in which healthy people have been denied insurance or jobs based on genetic "predictions." In April 2001, US-based railroad company Burlington Northern Santa Fe Corporation, agreed to stop requiring genetic testing of employees under threat of a lawsuit. The company had required employees who claimed work-related carpal tunnel injuries to submit to blood tests, which included searching for a chromosome 17 deletion, a genetic cause of carpal tunnel syndrome.[55] Last year, an 18-year-old Australian man with a family history of Huntington's disease was told by a government official that he would be hired only if he submitted to a genetic test demonstrating that he did not have the gene for Huntington's.[56]

HyPEd Warriors

"…As long as social norms of acceptable drug use are observed, the Army should welcome drugs that could ease the adjustment to another time zone or to longer periods without food or sleep; the Air Force should welcome a drug that could increase the G-force a pilot can endure before blacking out; and the Navy should welcome a drug that could ease motion sickness. To be acceptable, the drug technologies must be both safe and reversible. Guaranteeing that soldiers will be able to return to their original physiological profile (excluding normal wear and tear) will be very important…The army should lead the way in laying groundwork for the open, disciplined use of genomic data to enhance soldiers' health and improve their performance on the battlefield."

Source*: Opportunities in Biotechnology for Future Army Applications*. 2001. Board on Army Science and Technology Division on Engineering and Physical Sciences, National Research Council, (National Academy Press, Washington, DC.).

Memory Enhancement: When you eat your Smarties

"Because the brain is such a finely equilibrated and dynamic system, with great capacity for self-adjustment and control, the effect of disrupting its biochemistry by flooding it, via a pill, with some drug … is more likely to be the equivalent of trying to retune a radio or reprogram a computer by jamming a screwdriver into its circuit boards"

British neurologist Steven Rose cited in David Shenk, "One pill makes you smarter." *FEEDmag.com,* June 21, 1999.

Scientists call the drugs being developed to improve memory "cognitive enhancers" or "nootropics" – meaning 'acting on the brain' in Greek – though the drugs are more commonly known by consumers as 'smart drugs' or 'smarties.' The market for smart drugs is already massive. Nootropics used to alleviate dementia in those with Alzheimer's disease were worth US$94.5 million in 1995 but the illicit market is unknown. A quick Internet search brings up dozens of companies specializing in the sale of nootropics to Americans, drugs that are not approved by the US Food and Drug Administration (FDA).

Pharmaceutical companies, recognizing the profit potential of the drugs, are using genomics in their race to fill the growing demand for nootropic therapies. Lack of

understanding about the interactions has many worried about the long-term effects of such therapies. The excitement over using genomics to improve memory and intelligence reached a peak when, in September 2000, a scientist at Princeton University inserted an extra copy of the gene for a particular brain receptor into a mouse – nicknamed "Doogie," after the young medical prodigy on television. The "Doogie" mouse performed better than other mice on mouse intelligence tests. Articles hailed the research as a step towards creating drugs and genetic alterations to decrease age related dementia and improve human memory generally. Less reported in the media, however, was an article published in the April 2001 issue of *The Scientist* suggesting that Doogie's increased intelligence came at the price of vastly increased sensitivity to chronic pain.[57]

- *Brain Viagra?* In 1995, the famous Cold Spring Harbor Laboratory created a fruit fly with an apparently photographic memory. Later, the lab partnered with the pharmaceutical giant Hoffman-La Roche of Basel, Switzerland to see what they could do with the human mind (and economy). In late April 2000, Roche Pharmaceuticals announced a major scientific breakthrough in learning and memory that could lead to treatment for diseases with cognitive deficits such as Alzheimer's, depression, schizophrenia or aging. Drugs currently not proven, tested, or approved for use as memory enhancers – or in some cases not approved for any use in the US – but used for memory and easily available are Piracatum, Hydergine, Centrophenoxine and Vasopressin.
- *After Shock:* After demonstrating that the fruit fly's ability to learn could also be abolished by subtle genetic alterations,[58] researchers, Tim Tully and Jerry Yin of Cold Spring Harbor Laboratory began a company called Helicon Therapeutics to make drugs aimed at different brain molecules. They see lucrative future markets, not only for drugs to boost failing memory, but also for pharmaceuticals that could be given after traumatic events to prevent recollection of the incident. Currently they are in the second phase of testing their "memory drug," the last step before the FDA approval stage begins and the drug is tested on humans. The process could take as little as two years.
- *Brain Teasing:* In March 2001, the journal *Cell* published an article reporting that scientists had genetically engineered rodents with enhanced memory that persists until researchers use genetic trait control technology to switch off a key enzyme governing memory. .[59]
- *Social IQ:* Those who exhibit social behaviour at odds with society may be subjected to genetic therapies to 'cure' them of differences such as depression, obsessive behavior, hyperactivity and so on. Even shyness is now being treated with the drug Seratox – originally developed as an anti-depressant. A recent study[60] determined that a gene inherited from the father may act to fine-tune a part of the brain involved in social abilities. Based on this information, researchers are hoping to improve social skills in children who do not 'perform' socially.

Enhanced image:

In a world where beauty and image are the gods of consumerism, the possibilities for genetic manipulation of the human body are virtually endless.

- *Breasts or Bust:* On May 23, 2001, *New Scientist* magazine reported that researchers had found a method of allowing women to grow their own breasts.[61] Tissue is grown 'on site' through a patented technique of the

Institute of Microsurgery in Melbourne, Australia. The researcher, Kevin Cronin, predicts that the financial backing to develop his new technology will centre on cosmetic surgery applications, rather than breast reconstruction after mastectomy. "There is an obvious spin-off into breast augmentation and facial aesthetic surgery," he says. Other scientists, such as Dai Davis, a plastic surgeon from Stanford Hospital in London and Julia Polak from Imperial College School of Medicine in London, worry that the technique could increase breast cancer risk and will be very difficult to control.[62] Researchers admit they have not yet found a way to 'control size and shape.'

- *Fat Profits:* Finding a pharmaceutical product to help people lose weight represents a potentially massive market for the industry. In the US alone, the weight loss market is worth $33 billion annually. The market for prescription drugs for weight loss is worth $0.5 billion and this commercial potential, while great, has just been hit by the withdrawal of the two leading drugs, Reduc and Pondimin. However, the market for diet drugs is still growing at a rate of 8% per year.[63] The drugs are mostly created for the treatment of obesity and diabetes; however, the potential use of the drug for cosmetic weight loss is not lost on the drug companies. Xenical, for example, a diet drug produced by pharmaceutical giant Roche, has been nicknamed the "bikini drug."[64] In May 2001, *Time* reported sales of the drug have exploded over the Internet, where clients don't have to prove they need the drug.[65]
- *Wrinkle-Free Profits:* The market in anti-aging therapies, especially for lessening wrinkles, is the fastest growing sector of the $10 billion global cosmeceutical market.[66]

Sporting new genes:

"Genetic engineering in sport will foster not only a greater potential health risk for athletes than does conventional doping, but also a greater potential for performance enhancement"

> Dr. Jacques Rogge, Belgian surgeon, International Olympic Committee delegate and vice chair of its medical commission.[67]

Sport is virtually synonymous with performance enhancement. Athletes, who are inherently risk-takers, are often willing to put their health at risk in order to excel in their sport. The extent of that risk taking behaviour became obvious in a 1995 survey where nearly 200 aspiring American Olympians were asked if they would take a banned substance that would guarantee victory in every competition for five years and would then cause death; more than half answered yes.[68] Genetic enhancement's greatest appeal to athletes is, perhaps, that it will be very difficult to get caught. In particular, using genetic use restriction technology (GURTS), dubbed "Traitor" and "Terminator" technology by RAFI (now ETC Group), which could turn genetic enhancements on or off, will make it virtually impossible to detect.

- *Muscle Bound*: In early 2001 researchers created a breed of muscled, super strong mice through a genetically engineered process to produce a growth-promoting protein called muscle insulin-like growth factor 1 (mIgf1) in their muscles. The protein holds the potential to prevent the muscle decay caused by aging and by certain muscle diseases.[69] Migfl1 is now reportedly being used illicitly by athletes to increase muscle size and strength.[70] Christopher Evans is a researcher at the University of Pittsburgh and has been working on gene therapy that encourages dying muscle cells to grow. Though the research is meant to treat diseases such as Muscular Dystrophy, Evans reports being called by a sports medicine doctor who "put two and two together" and wanted to use the treatment for healthy athletes.[71]
- *Just Breath:* A gene that codes for the hormone erythropoietin or EPO, which regulates the production of red blood cells, has been identified. A synthetic version now serves as a wonder drug for patients suffering from anemia, AIDS or cancer. Because it enhances oxygen-carrying capacity, EPO is in widespread use in such endurance sports as cycling and distance running.[72]

- *A growing market:* Human growth hormone (hGH) has been used for decades in children who do not produce normal amounts of hGH. The hormone increases the height of children who are hormone-deficient, although they generally remain much shorter than average. The hormone used to be extracted at fairly high cost from the pancreas of human cadavers. Genetic engineering has now permitted the mass-production of hGH. Although the hormone therapy is only approved for use in hormone-deficient children, Eli Lilly (for the drug Humatrope), Genetech (for Protropin), and other companies annually supply an hGH market worth hundreds of millions of dollars. The drug is being tested for its effects on muscle mass in elderly patients and as a growth stimulant in short children who do not have a hormone deficiency. An illicit market for hGH has begun among body builders.[73]

Industry Interests

National regulatory agencies for pharmaceuticals are oriented toward treating diseases in a medical context and have not shown much interest in approving drugs that simply improve people's memories, boost intelligence, prevent sleep or make people taller. To get approval for drugs that might be used for performance or lifestyle enhancement, the pharmaceutical companies are directing their efforts toward gaining approval for their drugs as treatments for compelling medical problems such as Alzheimer's disease, multiple-infarct dementia, senility, narcolepsy, Turner's syndrome and so on. A sampling of pharmaceutical companies doing research on drugs that could have potential enhancement implications include:

Big Pharma's Focus on Potential Human Performance Enhancement Activities

Company	Pharma Sales (US) Millions 1999/2000	Pharma Profit Margin	Enhancement Activities
GlaxoSmithKline (merged Glaxo Wellcome and SmithKline Beecham)	$22,209.5	30.9% (Glaxo) 25.1% (SKB)	Company motto: "do more, feel better, live longer" *-anxiety, social disorders, PMS, post traumatic stress disorder, generalized anxiety, obesity, cognitive impairment, smoking cessation, depression, ADHD* -"*Paxil benefited throughout the world from its new indication for Social Anxiety Disorder" (Annual General Report)* -GlaxoSmithKline has asked for approval for Paxil for generalized anxiety disorder and post traumatic stress disorder
Pfizer (includes Warner Lambert)	$20,500	N/A	-herbal supplements for mental sharpness (Qunaterra) -Viagra for sexual dysfunction -spends 1.7 billion on genetic research -research on frailty, loss of mental acuity and sexual function
Merck & Co. (New Jersey)	$17,481.6	26.4%	-research and development activities in the area of anxiety cognition, depression, obesity
Astra Zeneca	$14,834	18.3%	-spending 2.5 billion in R&D -Inderal – beta blocker and other anxiety drugs
Eli Lilly & Co			-makers of Prozac "There is no question that we and other companies are working on things that can enhance cognition," Lilly Research Labs

Source: ETC Group; based on company websites and data provided by Scripp's Pharmaceutical League Table, 2000.

Drugs that are developed for the pharmaceutical industry to treat particular ailments often have a corollary use that has a high market value. A sampling of diseases and their performance enhancement corollary include:

Related Disease and Human Performance Enhancement Pharmaceuticals

Target Disease	**What's it worth?**	**Human Performance Enhancement Use**	**What's it worth?**
Diabetes/Obesity	In 1999, the US market for diabetes drugs totaled $2.9 billion at the manufacturers level. The market will grow to an estimated $ 4.5 billion by 2004. [74] Prescription drugs for weight loss currently total US$ .5 billion	Diet drugs - "the bikini drugs"	The weight loss market in the US alone is worth about US$33 billion annually.
Muscular diseases such as Muscular Dystrophy and age related muscle wasting	No data	Sport enhancement	The heavy demand for anabolic steroids has given rise to a black market in the US, with sales estimated at $400 million a year in 1991.[75]
Sexual dysfunction	In 1995, the prediction was that therapeutics for erectile dysfunction could reach US$70 million by 2000. Products to treat impotence accounted for 1.6% of the total genito-urinary therapeutics market in 1995. [76]	Sexual Enhancement	Sales of Viagra alone, for the treatment of erectile dysfunction topped $1 billion in 2000.
Alzheimer's	$3.6 billion by 2005	Smart drugs also called "nootropics"/ "cognitive enhancers"	$94.5 million in 1995
Breast Surgery following mastectomy	In the US, approximately 15,000 breast cancer patients chose to have breast implants placed after mastectomy in 1998. [77] In 2000, there were 78,832 reported breast reconstructions, but this figure includes implant removal and replacements.[78]	Cosmetic surgery for breasts and other body parts	Approximately 135,000 women in the US had breast implant surgery for cosmetic reasons in 1998. [79] Total reported cosmetic surgery procedures by U.S. board-certified plastic surgeons were 1,355,793 million in 2000. Numbers may represent only half of the total, as many practitioners do not engage in reporting. Revenues from the surgeries grew from $4.4 billion in 1997 to $5 billion in 1998 and $5.8 billion in 1999.[80]

The civil society agenda: The Optimism Gene

The strategy of the tethered lamb is common to many cultures. To trap a predator, you stake a lamb in a clearing and await your enemy. The strategy of the Gene Giants is similar except they don't need to 'off' their adversary – only keep us distracted long enough to make off with the real prize. Sometime in 2002 (but possibly before the end of this year) a bouncing baby, the cloned, impossible dream of barren parents, will gurgle onto our TV screens - poster prop for the new genomics. Or, is this the "tethered lamb" (Dolly?) that the pharmaceutical industry hopes will draw the opponents of commercial genetic engineering away from industry's real target? The companies, wrapped securely in the sheep's clothing afforded by their tethered sacrifice, may be jerking our genome in greener pastures.

Imbued as advocacy groups are with the optimism gene – a defect for which the industry is striving hard for a therapy – civil society organizations (CSOs) must focus on the issues raised by the new genomics.

Frame and fronts: Most importantly, we must enlarge the debate on agricultural biotechnology to encompass human genomics. We must take on the pharmaceutical industry directly and on all fronts. The pharmagenomics industry is one of the most powerful lobbying machines in the world.

The most critical factor in taking up this challenge is the capacity of CSOs to construct a strong coalition with those groups targeted by industry itself: disease and disability groups, indigenous peoples, women and the poor. (Advocacy CSOs are already a significant part of the "dissent" group.)

As is usually the case, "victory" will go to the side that first names the issues and establishes the battlefield. CSOs must move immediately to claim the high ground and identify the fora for the initial encounters.

Summitry: Agbiotech issues and human genomics are joined at the stomach. Generation 3's nutriceuticals and farmaceuticals (see *RAFI Communiqué*, November-December 2000) bring food and health advocates together. CSOs in these fields could begin a dialogue on strategy in the lead up to the World Food Summit Five Years Later ("*Food Fifth"*) originally scheduled this November.

However, the concentrated political push should be in the process that will culminate in the World Summit on Environment and Development in Johannesburg in September 2002 - also known as "Rio+10". This global review of the 1992 Earth Summit's "Agenda 21" should allow CSOs to raise the outstanding issues surrounding human genomics and human genetic diversity.

Critically, these meetings must include the participation of targeted groups that are too often excluded from the discussion. Governments and CSOs must ensure that these groups have a place within their respective delegations.

Special Session: The primary goal in Johannesburg would be to gain broad governmental support for a Special Session of the United Nations General Assembly on Genomics and Genetic Resources that should be held in New York in September 2003. A wide-ranging General Assembly debate should, in turn, assign follow-through responsibility to the various UN agencies and organs that should logically play a role in the intergovernmental monitoring and regulation of genomics.

Specialized agencies: In the meantime, there is no need to postpone obvious work on specialized UN agencies and programmes.

WHO: Most clearly the World Health Organization (and its annual intergovernmental Assembly) must be urged to address the full range of human genomics technologies and concerns. The Assembly convenes in Geneva every May and the 2002

session should be focused on human genomics issues if for no other reason than to forestall the WHO from losing its traditional "turf" to other institutions. It is WHO's failure to meet its responsibilities that forces CSOs to adopt additional approaches.

The WHO must also be urged to listen more carefully to the groups targeted by this research and to involve them in decision-making processes. A critical review of their past approach towards the target groups is also necessary, particularly their continued insistence on treating disability fundamentally as a medical problem.

Office of the UNHRHC: In recent times, the UN Human Rights Commissioner has enjoyed increased status and has shown a willingness to take on tough and unconventional issues (such as intellectual property). Given its historic involvement with women's rights, disability groups and indigenous peoples, the Human Rights Office is in an excellent position to consider the new genomics from the point of view of international human rights law. The UNHCHR should undertake to strengthen and develop the Universal Declaration on the Human Genome and Human Rights of UNESCO into a legally binding convention under its auspices. The Commission's major sessions usually take place in the June-August period in Geneva.

CBD: The Convention on Biological Diversity (created at the Rio Earth Summit of 1992) has technical responsibility to manage all of biodiversity, including that of human kind. Pressured by OECD governments, the Convention has been afraid to address the topic. At its next Conference of the Parties in The Hague in April 2002, governments should agree to place the problem before the Johannesburg Summit in September.

Other bodies: Several other UN bodies, especially UNESCO's Bioethics Committee and the International Labour Organization (ILO), could play a useful role in addressing at least some elements of the genomics issue. In particular, UNESCO should ensure that its Universal Declaration on the Human Genome and Human Rights, adopted in 1997, should be moved to the UNHCHR.

In summary, there are a series of international intergovernmental meetings and events beginning in November this year and resuming from April to September 2002 that could be important in pressing the genomics agenda. However, our strongest ally in this process will almost inevitably be headline news. The cloning of a human infant and/or other scientific developments we cannot now imagine will propel these issues onto the world stage bidden or unbidden.

The Action Group on Erosion, Technology and Concentration, formerly RAFI, is an international civil society organization headquartered in Canada. The ETC Group (pronounced Etcetera Group) is dedicated to the advancement of cultural and ecological diversity and human rights. Our new web site, www.etcgroup.org ***is under construction. All RAFI and ETC Group's publications are available at:*** **www.rafi.org**

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The Action Group on Erosion, Technology and Concentration, formerly RAFI, will release a series of new reports in 2001. Look for the following issues of *The ETC Communiqué* on our web site from September to December. Until our new ETC Group website is completed please look for all of our publications at: http://www.rafi.org:

- ***"New Enclosures: Alternative Mechanisms to Enhance Corporate Monopoly and BioSerfdom in the 21st Century"***
- ***Globalization, Inc. Concentration in Corporate Power: The Unmentioned Agenda***
- ***"Nanotechnology – Spiraling down from Genomes to Atoms"***

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