

**Brief**

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# Genomics: an NGO and civil society perspective

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#### The Programme on NGOs and Civil Society

Worldwide, the role of civil society has been increasing at rapid speed. Non-governmental organizations (NGOs) have become significant and influential players and generate much interest. Created in 1986, the Programme on Non-Governmental Organizations and Civil Society aims at contributing towards a better understanding of NGOs and the solutions of complex and conflictive societal problems involving NGOs.

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## ABSTRACT

Many NGOs and civil society organisations have not engaged in the broader genomics debate, but remain focused on Genetically Modified Organisms (GMOs) as they relate to food safety, food security, and the environment. Genetic engineering is but one aspect of genome sciences. Where is civil society in the rest of the genomics discussions? Why have NGOs largely ignored this important area of research?

Because CASIN has published work on NGO involvement with genetically engineered (GE) food, this report will not revisit that debate in detail. It does, however, consider whether the anti-GE food movement has revised its position with new developments in gene technology. The report primarily aims to examine genomics from the health perspective. How is civil society responding—or not—to these rapidly emerging technologies? What are NGOs' positions on stem cell research and gene therapy, technologies with potential for treating major diseases? For NGOs that have taken positions on these topics, the chief question is this: Under what conditions do CSOs support/oppose genomics and why?

We find that environmental groups are still the most active in raising awareness and promoting public education around genetically engineered food and its possible implications for ecosystem and human health. Development organizations join them in questioning the impact of gene technology on poverty. They point to issues of control over gene technology and consequent food insecurity. Some development NGOs do support genomics as a means to ensure food security and livelihoods. Indigenous Peoples and human rights groups are also concerned with the control and misuse of genetic material, specifically patents and intellectual property. Faith-based groups largely focus their attention on reproductive technologies and stem cell research. To what extent should humans play God/Creator? Communities of colour and disability rights advocates challenge the ethics of technology that could further legitimise eugenic selection and “genism” (discrimination based on genetic traits). Many patient support groups embrace genomic developments that make treatment of diseases possible. Finally, a few new “Genomics” NGOs have appeared on the scene, completely engaged in monitoring developments in genetic technologies from a public interest, social justice, environmental protection and global inclusion perspective. There is no shortage of work.

## INTRODUCTION

Europe and North America view the field of genomics as key emerging technologies that will fuel the knowledge-driven economy of the future. Advances in this field blur the boundaries between the pharmaceutical, biotechnology, agribusiness, chemical, energy and cosmetic sectors.

Genome science extends beyond the Human Genome Project to embrace genomic characterization of crop plants, agricultural animals and fish, forest trees, fungi and bacteria (including pathogens), viruses and parasites. Combined with genetics, bio-informatics and related tools, genomics is already transforming biologically based industries of pharmaceuticals, medicine, agriculture and food.<sup>i</sup>

Health proponents of genomics and proteomics research argue that advances in this field will help to predict disease progression, quicken their diagnosis, and identify new therapeutic targets for illnesses. Diseases for which a cure seems most promising include leukemia, diabetes, breast and prostate cancer, Alzheimer's disease, Parkinson's disease, spinal cord injuries and Huntington's chorea. Scientists are also experimenting with genetic and fetal tissue research to repair and regenerate human tissues, skin cells and nerve cells.

Scientists have already tested the engineering of mosquitoes to be resistant to the malaria parasites they host, thereby reducing their ability to transmit the disease. Food vaccines in the form of bananas were being genetically modified to produce vaccines for illnesses ranging from Hepatitis B to tooth decay and traveller's diarrhea. Foods that can target specific vitamin and nutritional deficiencies are also under development<sup>ii</sup>. The possibilities seem endless. Outside of human health, expected benefits of research in this field include improved agricultural productivity, environmental protection, and better forest management.

The genomic era is well underway. Yet institutional mechanisms for monitoring research, development and application, as well as the public debate required for setting public policy, is still lagging far behind industry. As with many other scientific discoveries, genome science provokes discussion on the ethical, social, and political contexts and consequences of its development and application. The governments and private sectors of EU, Canada, USA, Australia, New Zealand and Japan are heavily investing in genomics. What do their people think about this technology? How can we, as a global community, ensure that genomic applications will be properly researched, developed, and applied? How can we ensure they will benefit the poor?<sup>iii</sup>

Support/opposition dichotomies among civil society organizations (CSOs) are relevant to certain aspects of genome sciences, but determining a policy position on the broader application of these emerging technologies is complicated by numerous factors. For example, global opposition of civil society mounts against genetically modified (GM) food, many aspects of human and animal genetic engineering, and the bio-tech companies who increasingly exert control over our lives and environment. The most outspoken NGOs “opposing” genomic technology– such as the ETC group (formerly RAFI), Greenpeace, and Corporate Watch– argue that while researchers rush to harness the “virtual information” of the genome, the potential social benefit from their findings are minimal because of the control exercised by transnational business who respond to the profit motive.<sup>iv</sup> By contrast, non-profit research centres such as the International Rice Research Institute (IRRI) and the Genetic Interest Group are genuinely interested in the potential of genomics for enhancing the livelihood of poor farmers in the South, and treating diseases. For Greenpeace, Corporate Watch and the ETC Group, is it a question of *control* over the technology, the *technology* itself, or particular *applications* of the technology? Can the IRRI assure that its research enhances food security, rather than binding farmers to corporations who own patents for their rice? The Genetic Interest Group may support gene therapy, but is it also in favour of human cloning if this could somehow help to treat diseases, too?

Thus the question to ask is not who supports or opposes genomics and why. Rather, the concern is this: *under what conditions* do CSOs support/oppose genomics and why.

## WHAT IS GENOMICS?

Genomics refers to the mapping, sequencing and analysis of the full set of genes of different organisms or species. The science sheds light on, and makes possible an array of technologies including biotechnology, genetic modification of organisms (GMOs), proteomics, nutrigenomics, cloning, and stem cell research.

Genomics entered the scene in the 1980s. By the 1990s, it had taken off, initiating genome projects for several species. The human genome has been of most interest to governments, foundations and companies seeking commercial applications of the science. Industry speculators, however, suggest that agricultural genomics may yield faster benefits than human genomics, as it is generally easier and less controversial to utilize genetic information from plants and animals<sup>v</sup>. Research in the biotechnology industry has certainly moved ahead quickly, although its outcomes have not always met with support.

### Useful Definitions

**Genomics** aims to decipher and understand the entire genetic information content (i.e. the genome) of an organism. It uses automated laboratory equipment and high-power computers to map, sequence and analyse genetic information. Consequently, this science underpins all biological (and biotech) research. “It differs from classical biological research in its large scale, broad scope and intense reliance on data collection, analysis and information technology (bioinformatics). Genomics may offer new therapeutic and diagnostic methods for some diseases. Other applications are in the food and agriculture sectors.

**Genetics**, a related field to genomics, is the study of genes and their role in inheritance.

**Proteomics** is the quantitative and qualitative study of the proteins related to a genome, and inquires how proteins work under different conditions in cells. Often viewed as the "next step", proteomics is much more complicated than genomics, but complements the genomics approach. Proteomics has applications in the pharmaceutical and diagnostic industries, and has already made significant progress in cancer research.

**Nutrigenomics** (nutritional genomics) explores the links between genes, health and diet. It is the application of the sciences of genomics, transcriptomics, proteomics and metabolomics to human nutrition. Its proponents extol the possibility of longer, healthier lives by following a diet “customized” to one’s genetic make-up.

**Biotechnology** encompasses a number of techniques that involve the use and manipulation of living organisms to produce commercial products. These techniques include cell culture, tissue culture, embryo transfer, and recombinant DNA technology (genetic engineering).

Sources: Wikipedia <http://en.wikipedia.org>, Genome British Columbia’s Learning Centre <http://www.genomicseducation.ca>, The Action Group on Erosion, Technology and Concentration [www.etcgroup.org](http://www.etcgroup.org).

## CIVIL SOCIETY INVOLVEMENT

Given the enormous implications of emerging technologies such as genomics, several commentators have questioned the “absence” of a civil society movement in this field. While there are reasons that help explain this observation, it is important to examine what civil society *is* doing, and how it endeavours to address what it sees as the “democratic deficit” in development of genomics public policy<sup>vi</sup>.

Civil society organizations (CSOs) representing Indigenous Peoples, environmentalists, faith communities, human rights advocates, disability rights, medical and scientific associations, coloured communities, and development NGOs have taken on genomics at various levels. Many CSOs oppose “irresponsible” applications of the emerging technologies, basing their criticism on social, ethical, theological, environmental, health, and economic justice concerns. Staunch opposition for cloning and inheritable genetic



modification (IGM) coincides with a cautionary approach to stem cell research. Many organizations have not issued policy papers or public statements on their views about genomics, possibly because they feel ill-prepared to make an informed decision in an area so new.

CSOs keep an eye on developments in genetic technologies, raise public awareness, and conduct education. They also lobby national and international bodies, bring cases before court, and engage in ethical debates with the scientific and academic community.

## **NGO TYPOLOGY: WHO IS INVOLVED AND WHY?**

### **Environmental NGOs: Genetically Engineered Food**

Environmental NGOs' (ENGOS) involvement with genomics is largely traced back to the onslaught of genetically engineered (GE) food. Organisations like Greenpeace and Friends of the Earth were successful in gaining attention from other CSOs who banded together to oppose genetically modified organisms in all their forms. ENGOS contend that the environmental impacts of genetic engineering are hazardous and irreversible. Their main arguments against GE are that it endangers local biodiversity, can create invasive species, and contaminate farmers' varieties. In addition, it can increase pesticide usage and result in new, stronger viruses, all of which could have serious effects for human health.

The health impacts of GE foods are uncertain, but many health professionals are especially concerned about their effects on infants and people with (compromised) immune systems. Research in this field points to allergens, reduced nutritional quality, uncertain toxic effects, and antibiotic resistance. GE proponents claim the food is safe, but contradictory evidence suggests such assurances are premature. NGOs call for precaution— not profit— to determine how society should proceed in the face of uncertainty.

### **“Genetically Tailored” Food**

Nutrigenomics is an emerging science that explores the links between genes, health and diet. Some individuals in the biotech and pharmaceutical industries are jubilant with its prospects for improving health and preventing disease. Guy Miller, chairman and CEO of Galileo Laboratories, Inc., a biotech company developing cell-based therapeutic nutritional products asserts that, “Nutrigenomics will revolutionize wellness and disease management. Specifically, by being able to elucidate genetic profiles of individuals, diets will be formulated from crop to fork to confer prevention or retard disease progression. As basic science advances converge with e.commerce, new opportunities will emerge to deliver to consumers, whose genetic susceptibility to specific diets and diseases are

known, products tailored to individual dietary needs.”<sup>vii</sup>

While nutrigenomics has not attracted much attention from the NGO community, GeneWatch UK and the Council for Responsible Ethics are actively campaigning in this field. They work to raise awareness of the faulty claims behind genetic testing, and push for “statutory regulation of genetic tests and an end to direct to consumer sales”. GeneWatch UK contends that, “Without proper regulation, the misleading marketing of genetic tests may soon increase exponentially and this corner of the knowledge-based economy will be based on advertising spin and not on fact. What will it mean for people’s health if the human genome becomes the basis of a massive marketing scam?”<sup>viii</sup>

In collaboration with Demos and the Food Ethics Council, GeneWatch hosted a seminar in April 2005 on the benefits and implications of nutrigenomics for consumers and public health. They explored why businesses and governments are investing in the field, and potential impact on the production and consumption of food.

### **Emerging Diseases**

The Third World Network has recently drawn attention to genetic engineering and a world public health crisis resulting from the re-emergence of infectious diseases.<sup>ix</sup> The report asserts that, “current strains of many pathogens are resistant to known treatments, some to nearly all known drugs and antibiotics. There can be little doubt that it is the transfer of genes across unrelated species of animals and plants (i.e., horizontal gene transfer) that is responsible for the development of drug and antibiotic resistances. The phenomenal increase in virulent infections and antibiotic resistance coincides with the commercialisation of genetic engineering biotechnology.”

By facilitating horizontal gene transfer and recombination, the authors question the extent to which genetic engineering biotechnology is contributing to the emergence and resurgence of infectious, drug-resistant diseases. They also point out that the overuse and abuse of antibiotics in intensive farming and medicine has yet to be considered in genetic engineering biotechnology. They call for an enquiry into the potential contribution of genetic engineering biotechnology to the etiology of infectious diseases.

### **Development, Agriculture and Poverty**

In the development field, civil society, scientific bodies and governments have denounced the development of chemically-dependent plants and genetic seed sterilization as an immoral application of biotechnology that imperils farmers, food security and the environment.

The Action Group on Erosion, Technology and Concentration (formerly RAFI Rural

Advancement Foundation International, now ETC Group) is one of the earliest and most active NGOs in the field of genetic technology.<sup>x</sup> Since 1993, its research on human genomics has emphasized human performance enhancement (HyPEs) therapies and drugs, and on those members of society who are most vulnerable to exploitation by genomics technology. The Group contends that “any major new technology introduced into a society which is not, by its nature, a 'just' society will exacerbate the gap between rich and poor.” Consequently, the ETC group was at the forefront of raising awareness of “Terminator” and “Traitor” technologies in the late 1990s.<sup>xi</sup>

The ETC Group is not fundamentally opposed to genetic engineering, but it has deep concerns about its application—often forceful imposition in many parts of the world. The Group investigates the potential and existent social and economic impacts of new biotechnologies. It contends that in the present social, political and economic situation, genetic engineering is not safe, that the risk to people and the environment is (unacceptable). Control is the primary issue for ETC group. The organization campaigns with other civil society organizations across the globe to ban Terminator and Traitor technologies. In 2005, the ETC hosted a workshop, “New Technologies, Agriculture and Corporate Power” at the World Social Forum in Brazil (26th-30th January). Discussions touched on nanotechnology, genomics, human enhancement technologies and new forms of Biopiracy.

Corporate Watch continues to be outspoken in its opposition to GMOs.<sup>xii</sup> The organisation monitors the countries involved in cultivation of GMOs and critically analyses industry claims that such crops will feed the Third World. Corporate Watch shares the view with the ETC group that biotechnology exacerbates inequalities underpinning the causes of hunger. Corporate-controlled patents and intellectual property rights will not address poverty, maldistribution of food, and lack of access to land, they say.

Along with environment NGOs, Corporate Watch highlights the potential environmental risks that jeopardize sustainability of small farming systems and human health, such as the production of environmental toxins that move through the food chain, as well as polluting water and soil. “There are agroecological alternatives to biotechnology that result in technologies that are cheap, accessible, risk averting, productive in marginal environments, environment and health enhancing, and culturally and socially acceptable. Policies must be put in place to promote the upscaling of successful agroecological interventions, that are already reaching about nine million small farmers at one-tenth the cost incurred by official international agricultural subventions.”<sup>xiii</sup>

In contrast to development civil society organizations that oppose much research and applications of genomics, the International Rice Research Institute (IRRI) does not. The Philippines-based Institute focuses on agricultural research, its application, and training. The Institute’s objective “is to find sustainable ways to improve the well-being of present and future generations of poor rice farmers and consumers while at the same time

protecting the environment.” IRRI mainly collaborates with national agricultural research and development institutions and farming communities to carry out its research.<sup>xiv</sup>

IRRI has recently formed the International Rice Functional Genomics Consortium that represents 18 institutions from 10 countries and two international agricultural research centres.<sup>xv</sup> Its founders expect the IRFGC to help facilitate communication and exchange of rice functional genomics data, increase leverage to initiatives submitted to respective governmental or international funding agencies, share materials, integrate databases, encourage bilateral or multilateral partnerships, and quicken delivery of research results to benefit rice production.<sup>xvi</sup> As with many agricultural crops including soy, corn, and wheat, through understanding their genome, scientists are exploring ways to not only increase crop yields, but also to boost nutritional values of food, either by adding new vitamins and minerals, increasing those that are already produced, or making nutritional content more “bio-available” (available to the body for digestion).

Africa, too, has established an organisation to advance biotechnology-related research, particularly in genomics. The new entity, known as the African Genome Policy Forum, is an example of the various forms created to engage policy makers, members of the scientific community and NGOs in the genomics field. The African Genome Policy Forum is also a rare example of North-South collaboration.<sup>xvii</sup> Genome Canada, a not-for-profit funding and information resource on genomics in Canada, and the University of Toronto were key players in launching the Forum. Peter Singer, the Director of the University of Toronto Joint Centre for Bioethics, refers to the initiative as an effort “to ensure developing countries do not lose out in genomics technology like they did in the green revolution and information technology.” Singer asserts that, “Developed countries should now bring capital to help poor nations develop genomics.” It was expected that similar platforms to the African Genome Policy Forum would be established in Latin American countries, India, and China with the aim to influence decision makers in their respective governments.<sup>xviii</sup>

### **Children’s and Family Advocates**

Many children's and family advocates are staunchly opposed to human cloning and inheritable genetic modification (IGM). They maintain that such technologies would have serious consequences for the physical, social and psychological well-being of all children. In addition, they assert that exposure to risk of genetic, developmental, social and psychological problems cannot be medically justified. Great improvements in the lives of children are achievable without genetic manipulation.<sup>xix</sup>

### **Patients Advocates and Professional Alliances**

Many patients advocacy groups and professional networks allude to “supporting research” in their particular fields of interest, but do not have public stances on genomics. As indicated by NORD’s statement below, this could be because the

technology is still so new that NGOS do not feel equipped to make an informed opinion. US-based National Organisation for Rare Disorders and the Fragile X Research Foundation are some of the organizations that do make reference to genomics, while the Genome Action Coalition and Genetic Interest Group appear to offer general support for research in the genomics field.

The National Organisation for Rare Disorders (NORD) is an alliance of roughly 140 not-for-profit health organizations and thousands of individuals and medical professionals serving people with rare diseases. Citing that most rare disorders are genetic, NORD “works to ensure that biomedical research will not be hampered or delayed, and that the fruits of genome discoveries will be made available to patients who need them.”

NORD’s policy on Gene patenting recognises that the, “code for the human genome belongs to the entire human race and should not be the property of any one individual or corporation”. NORD does not support patents for genes as they exist in nature. It does, however, support patents for genes that scientists have manipulated to create a commercial use, and for commercial products developed from genetic information. NORD argues that patent holders of commercial uses of genes should be obliged to license the use of the gene to any company that wishes to sell the treatment.<sup>xx</sup>

With regard to fetal stem cell research, NORD’s stance is that because the research is new and the outcomes unclear, “it is too early for NORD to take a policy position at this time.” It commits itself to “monitor progress in the public and private research sectors and re-visit the issue when appropriate.”<sup>xxi</sup>

The Fragile X Research Foundation, FRAXA, was founded in 1994 by three parents of children with Fragile X to support scientific research aimed at finding a treatment and a cure for the disease. The organization supports families affected by Fragile X and raises awareness of rare disease. It contends that research in this area holds promise for advancing understanding of other disorders like autism, Alzheimer's disease, and X-linked mental retardation. FRAXA’s mission is to accelerate progress toward effective treatments and ultimately a cure for Fragile X, by directly funding the most promising research including gene therapy, protein replacement, and pharmacology.<sup>xxii</sup>

The Genome Action Coalition (TGAC) is comprised of more than 130 members who include patient advocacy associations and foundations, professional groups in the genetics field, university-based research entities, and pharmaceutical research and biotechnology companies. TGAC was created in January 1995 by members who believed that the success of the Human Genome Project is critically important for the future of biomedical research and for health care.<sup>xxiii</sup>

The Genetic Interest Group (GIG) is a UK national alliance of organisations with a membership of over 130 charities that support children, families and individuals affected by genetic disorders. The organization follows developments in the UK and Europe that

will influence the knowledge transfer and understanding from the research lab into products and services for its member groups. Its regular mailings update member groups on a number of issues, encouraging them to become further involved. While no position papers were available, the organization asserts that, “In a potentially controversial field like genetics, GIG also provides a strong voice advocating the benefits of scientific progress in understanding the contribution being made now and that will be made in the years to come for improving health and combating many currently incurable diseases.<sup>xxiv</sup>”

### Communities of Colour

Pointing to the history of racism, communities of colour are especially wary of cloning, inheritable genetic modification (IGM), and other emerging genetic and reproductive technologies. They have seen science manipulated to justify discrimination, and are concerned that gross abuse of this technology could result in increased discrimination through "genism," and possibly a new form of eugenics. However, individuals also recognize the potential positive health advances of genomic applications, especially as they relate to diseases more common in their respective communities. For example, research indicates that African Americans experience a substantially higher rate of mortality from cancer, diabetes, and cardiovascular disease than Caucasians. African Americans are twice as likely to die of diabetes than whites. The incidence of diabetes among Hispanic/Latinos in the United States is nearly two times as high as non-Hispanic whites of similar age. All three of these diseases are genetically linked. However, in order for new genomic research to have any impact on health in these communities, health services for diagnosis and treatment must be available, accessible and affordable.<sup>xxv</sup>

### Indigenous Peoples

Indigenous Peoples, too, have expressed concern with advances in gene technology. Since 1993, the Indigenous Peoples Council on Biocolonialism (IPCB) has confronted issues of biopiracy (the privatization and unauthorized use of biological resource by entities not entitled to their use).<sup>xxvi</sup> Originally forming to oppose the Human Genome Diversity Project, it now assists indigenous peoples world-wide in the “protection of their genetic resources, indigenous knowledge, cultural and human rights from the negative effects of biotechnology.” In April

2005, the IPCB opposed the launch of a global genetic research initiative to collect Indigenous peoples’ DNA. Purporting to “help people better understand their ancient history,”

“Indigenous groups around the world are much more aware of biopiracy, and our own human and collective rights in research. In the past ten years, we have developed extensive networks of Indigenous peoples who are knowledgeable and active in defense of their rights.”

-Cheryl Smith, a Maori bioethicist from Aotearoa (New Zealand)

the National Geographic Society and the IBM Corporation, financed by the Waitt Foundation, planned to collect 100,000 DNA samples from Indigenous peoples around the world as part of the Genographic Project<sup>xxvii</sup>.

The IPCB likens the Genographic project to its pre-cursor, the Human Genome Diversity Project, a project they claim the National Science Foundation and UNESCO refused to support because it was so fraught with ethical and scientific problems. The IPCB suspects that by turning to the private sector, the Genographic Project is an effort to escape public and legal scrutiny.

Viewed as an unconscionable attempt by scientists to pirate Indigenous DNA for profit, the HGDP faced international opposition by Indigenous peoples who are now strong proponents of insuring human rights standards are entrenched in research. Another consequence of this past experience is that many Indigenous groups are highly suspicious of any genetic initiatives claiming to “ensure cultural preservation”. Maori bioethicist Cheryl Smith contends that, “If they (research companies) really want to help promote Indigenous peoples cultures there are more productive ways and methods for doing so.”<sup>xviii</sup>

Signatories to the Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project opposed the patenting of all natural genetic materials, and maintained that “life cannot be bought, owned, sold, discovered or patented, even in its smallest form.”

### **Disability Rights Advocates**

Among the earliest and most vocal opponents of new technologies of human genetic modification are disability rights advocates. Like communities of colour, these advocates also look to recent horrors of history such as the eugenic selection of Nazi Germany where more than 100,000 people with disabilities were exterminated in German medical facilities and concentration camps.

Many disability rights advocates also oppose existing procedures that are used to prevent the birth of children with particular characteristics, arguing that life with disability is worthwhile and a just society must accept and support all lives, “whatever the endowments they receive in the natural lottery.”

Disabled Peoples International (DPI), an international human rights organization committed to the protection of disabled people's rights, focused on the new human genetic technologies in a *Position Statement on Bioethics and Human Rights* in November 2000. In their paper, DPI called for the involvement of persons with disabilities, particularly women, at all levels in decision making concerning Bioethics. DPI also demanded the Bioethics debate be brought outside the realm of academia and made available and accessible to disabled people from all walks of life across the globe. It requested the development of instructional campaigns and training to counteract the discrimination and violations of basic human rights, which have been justified through

genetics and bioscience. Finally, it advocated that the concept of "person" not be linked to a certain set of abilities.<sup>xxix</sup> Other disability rights organizations aim their sights at introducing national legislation. For example, the American Association of People with Disabilities worked to pass new legislation protecting individuals against discrimination on the basis of genetic information.<sup>xxx</sup>

### **Human Rights Advocates**

Human Rights advocates underscore the “notion that human beings have inherent dignity, worth, and rights depends on recognition of our common humanity. Genetic manipulations that produce groups of biologically distinct people could easily unravel the progress that has been made over the past few centuries toward that recognition”. Many countries look to the framework of human rights when considering new human genetic technologies. This has shaped the international community. NGOs have been part of developing international declarations such as the Council of Europe's Convention on Human Rights and Biomedicine and UNESCO's Universal Declaration on the Human Genome and Human Rights.<sup>xxxi</sup> The Global Lawyers and Physicians for Human Rights maintains a Database of Global Policies on Human Cloning and Germline Engineering.<sup>xxxii</sup>

### **Faith-Based Groups**

Religious leaders from many faiths have overwhelmingly condemned reproductive cloning and inheritable genetic modification on the basis of social, ethical and theological grounds. Islamic and Christian views on cloning touch on the debate over to what extent the “will of God” can or should be altered by human action,<sup>xxxiii</sup> In the United States, Christian organizations engaged in the debate include various denominations, as well as professional medical, dental, and legal societies. In contrast, the U.S.-based Religious Action Center of Reform Judaism welcomed the introduction of therapeutic cloning.<sup>xxxiv</sup> Other analysis of Jewish law, however, acknowledges the contradicting obligations to help those who are in need (highlighted by the specific obligation to reproduce), and general inherent moral conservatism.<sup>xxxv</sup> A 1997 survey of seven Hindu leaders conducted by Hinduism Today revealed that all strongly called for strict regulation of human cloning.<sup>xxxvi</sup>

### **Scientists and Health Professionals**

Health professionals, medical researchers and scientists have a professional as well as a human interest in ensuring that medicine, science and technology enhance human well-being. Due primarily to safety considerations, there is general opposition to reproductive cloning and inheritable genetic modification (IGM) in the medical and scientific communities. Few scientists or scientific associations have publicly expressed their position in favour or against IGM. Human cloning and IGM could not be developed without tremendous risk to the altered fetuses, children, and the women who carry and bear them. Many publications, professional and academic forums debate the ethics of experimentation on human subjects. Developmental biologist Dr. Stuart Newman points



out that "no amount of data from laboratory animals will make the first human trials anything but experimental."

### Genomics-Specific NGOs

Several NGOs specifically focusing on genomics and other emerging technologies have responded to the "civil society deficit" in this field. GeneWatch UK is a not-for-profit group that actively monitors developments in genetic technologies from a public interest, environmental protection and animal welfare perspective. It addresses all aspects of genetic technologies such as GM foods and genetic testing of humans. GeneWatch advocates public input in whether or how these technologies are used. It also campaigns for safeguards for people, animals and the environment.<sup>xxxvii</sup>

Civil society coalitions are also forming to confront the rapidly changing field of genomics. For example, the UK-based Genetic Engineering Network is a network of people opposed to the imposition of GM technology. GEN includes local campaign and action groups NGOs, direct activists, and individuals campaigning against genetic engineering. The Network aims to "support, link and publicise" the movement.<sup>xxxviii</sup>

The Centre for Genetics and Society is an American-based non-profit information and public affairs organization.<sup>xxxix</sup> The Centre seeks to elucidate and promote human genetics policies based on human rights, social justice and global inclusion. It encourages responsible application and effective societal governance of the new human genetic and reproductive technologies. In collaboration with a network of health professionals, scientists, and civil society leaders, the Center "supports benign and beneficent medical applications of the new human genetic and reproductive technologies, and opposes those applications that objectify and commodify human life and threaten to divide human society". Along with the Committee on Women, Population & Environment, Manavi, and the National Asian Pacific American Women's Forum, the Centre is currently orchestrating its *Campaign to End Sex Selection*.

### THE FUTURE IS NANOTECH

Nanotechnology—the manipulation of matter at the scale of atoms and molecules —is another emerging technology that requires similar vigilance to genomics. Biotech and nanotech intersect in health and agriculture. In the field of health, both technologies have the potential to enhance the quality of life for human beings through medical diagnostics, drug delivery and customized therapy. On the farm, targeted pest management and the creation of high yield crops are a few overlapping research areas.

The ETC Group asserts that, "While nanotechnology offers opportunities for society, it also involves profound social and environmental risks, not only because it is an enabling

technology to the biotech industry, but also because it involves atomic manipulation and will make possible the fusing of the biological world and the mechanical.” The ETC Group calls for a moratorium on research involving molecular self-assembly and self-replication, and re-asserts the urgent need to evaluate the social implications of all nanotechnologies. It predicts that, over the next 20 years, the “impacts of nano-scale convergence on farmers and food will exceed that of farm mechanisation or of the Green Revolution”, and cautions that “no government has developed a regulatory regime that addresses the nano-scale or the societal impacts of the invisibly small.” A number of NGOs such as the US-based Center for Responsible Nanotechnology, Foresight Institute, and Netherlands-based Rathenau Institute are already concerned with this emerging technology, seeking to ensure that it be used to improve conditions in the broadest sense rather than for destructive or narrow purposes.

## CIVIL SOCIETY ENGAGEMENT IN THE POST-GENOMIC ERA

Some scientists assert that the complete sequencing of individual plant and animal genomes now allows for entry into the “post-genomic age” of applied genetics and proteomics. This era will focus on comprehending the structure and function of genes and the proteins that they encode, ultimately increasing knowledge of the mechanisms underlying human, animal and plant diseases. Application of that understanding is expected to revolutionize diagnosis, treatment and prevention of disease.<sup>xi</sup>

“We need to move with all deliberate speed to bring the new human genetic technologies within the ambit of responsible societal governance.”– Center for Genetics and Society

It will be some time before the international community grasps the full implications of the new human genetic technologies. But it will be much longer if nascent technologically-focused social and political movements do not step up to critically face the immense challenges these technologies pose. As part of this work, NGOs are calling for full public discussion on genomics, nanotech, and other emerging technologies. CSOs contend that society has lost much of its confidence in private and public science, that scientists should not “educate” society but that the public must determine the objectives, practices and developments of the technologies it finances. Genetics and Society calls on national and international leaders and members of civil society to inform themselves about critical aspects of the new human genetic technologies, to join together to build “a new civilizational commitment to fully engage this threshold challenge.”<sup>xli</sup>

## REGULATION

Intergovernmental oversight with consistent regulations concerning the collection, exchange, and use of human genetic diversity is crucial, NGOs claim. The protection of human subjects is, too. To this end, the ETC Group is pushing for a legally-binding International Convention for the Evaluation of New Technologies. Other steps in this direction include achieving global conventions banning inheritable genetic modification. In addition, a Treaty initiative to Share the Genetic Commons was launched in February 2005 at the World Social Forum in Brazil. Over 325 civil society organizations representing more than 50 countries have joined the project, which endeavours to prevent the industrialized North from pirating the genetic inheritance of the South.

Bill Joy, Senior Scientist and Co-Founder of Sun MicroSystems suggests a number of ways to proceed in the realm of emerging technologies.<sup>xiii</sup> He notes that while we will never understand the full extent of risks associated with new technologies, our constant boasting is evidence enough that we have *some* idea of technology's powerful potential. Joy proposes that scientists, like doctors, take an Hippocratic Oath to reduce the risk of abuse. At the very least, he insists that the precautionary principle be honoured. Joy also asserts that the market is a powerful mechanism. Noting that ethics are often reduced to a cost benefit analysis in Western, capitalist societies, he questions how the risks of emerging technologies could be monetized.

Future research will shed greater light on promising possibilities for, as well as dangerous consequences of applied genomics. Could scientists be on the verge of defeating diabetes and cancer? Will researchers find themselves applying genomics to treat diseases that have emerged as a result of the very same science? Whichever way the future unfolds, effective regulation of genomics and other emerging technologies is a major feat for public health. Given the potential of these technologies to be used for both noble and malevolent ends, their regulation also becomes central to national and international security. Will civil society evolve fast enough to keep pace with these emerging technologies, to ensure an element of civility—and responsibility— in modern science?

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