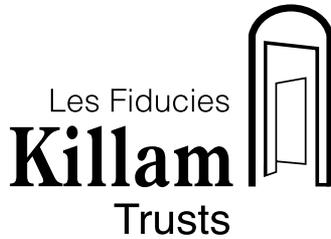


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LECTURE

**Biotechnology: The Human as
Biological Resource?**

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Canada Research Chair in Law and Medicine
Faculty of Law, Centre de recherche en droit public
Université de Montréal

Published by the Trustees of the Killam Trusts



Izaak Walton Killam

Born in 1885 at Yarmouth,
Nova Scotia.

Died in 1955 at his Quebec
fishing lodge.



*Dorothy Brooks Killam, née
Johnston*

Born in St. Louis, Missouri
in 1899.

Died in 1965 at La Leopolda,
her villa in France.

FOREWORD

The 2006 Killam Annual Lecture represents a series of departures from the past.

First, our brilliant lecturer – *Dr. Bartha Maria Knoppers* – spoke not on the (loosely) traditional theme of support for research, but on the ethical questions we must think about as we engage in medical and biological research.

Second, the Lecture took place in l'Assemblée Nationale in Quebec City, the city itself and a provincial legislature both constituting new locales for the event.

And thirdly, this Lecture will be the last to be printed and circulated to our Killam Scholars' mailing list of over 5,000; for 2007 and future years the Trustees have decided to "go electronic" by putting Dr. Knoppers' Lecture and those that follow on the Killam Trusts' website (www.killamtrusts.ca) in both printable and audio formats.

Dr. Knoppers is a world renowned expert in her field, and thus is uniquely qualified to give this important Lecture. She is former Chair of the International Bioethics Committee of the United Nations Educational, Scientific and Cultural Organization (UNESCO) which drafted the Universal Declaration on the Human Genome and Human Rights. She is a co-founder of the International Institute of Research in Ethics and Biomedicine (IIREB) and is affiliated with many similar organizations both in Canada and abroad. Her Killam Lecture entitled *Biotechnology: The Human as Biological Resource?* can truly be said to be "the last word" on this hugely important topic.

Dr. Knoppers' Lecture can be found on our website, or you can get more hard copies by writing to the Administrator of the Killam Trusts. Both addresses are found on the outside back cover of this booklet.



For copies of this lecture and others in this series (listed at the end of this booklet), go to our website: www.killamtrusts.ca or write our Administrative Officer at the address on the back.



The Killam Trusts

The Killam Trusts were established through the generosity of one of Canada's leading business figures, Izaak Walton Killam, who died in 1955, and his wife, Dorothy Johnston Killam, who died in 1965. The gifts were made by Mrs. Killam both during her lifetime and by Will, according to a general plan conceived by the Killams during their joint lifetimes. They are held by five Canadian universities and The Canada Council for the Arts. The universities are The University of British Columbia, University of Alberta, The University of Calgary, the Montreal Neurological Institute of McGill University, and Dalhousie University.

The Killam Trusts support Killam Chairs, professors' salaries, and general university purposes; but the most important part of the Killam program is support for graduate and post-graduate work at Canadian universities through the Killam Scholarships. In each of the Killam universities and at the Canada Council, they are the most prestigious awards of their kind.

The Canada Council also awards five Killam Prizes annually, in Health Sciences, Natural Sciences, Engineering, Social Sciences,

and Humanities. Worth \$100,000 each they are, as a group, Canada's premier awards in these fields.

To date over 5,000 Killam Scholarships have been awarded and 83 Killam Prize winners chosen. The current market value of the Killam endowments exceeds \$400 million.

In the words of Mrs. Killam's Will:

“My purpose in establishing the Killam Trusts is to help in the building of Canada's future by encouraging advanced study. Thereby I hope, in some measure, to increase the scientific and scholastic attainments of Canadians, to develop and expand the work of Canadian universities, and to promote sympathetic understanding between Canadians and the peoples of other countries.”

John H. Matthews

W. Robert Wyman, CM, LL.D., Chancellor Emeritus, UBC

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November 2006



PROFESSOR BARTHA MARIA KNOPPERS

**Canada Research Chair in Law and Medicine
Faculty of Law, Centre de recherche en droit public
Université de Montréal**

Bartha Maria Knoppers is Full Professor at the Faculté de droit, Université de Montréal, Senior Researcher at the Centre for Public Law (C.R.D.P.), Canada Research Chair in Law and Medicine and holder of the Chaire d'excellence Pierre Fermat (France). She is a graduate of McMaster University, (B.A.), University of Alberta (M.A.), McGill University (LL.B., B.C.L.), Cambridge University, U.K., (D.L.S.), Sorbonne (Paris I) (Phd.) and was admitted to the Bar of Quebec in 1985. She was born in the Netherlands and is married with two children.

Professor Knoppers worked with the committee of the World Health Organization (Geneva), as a consultant and is a Forum Fellow of the World Economic Forum (Davos) and now is member of the Professional Ethics Committee of the American Society of Human Genetics.

Former Chair of the International Ethics Committee of the Human Genome Project (HUGO), (1996-2004), she was a member of the International Bioethics Committee of UNESCO which drafted the Universal Declaration on the Human Genome and Human Rights (1993-1997). Dr. Knoppers is also Co-Founder of the International Institute of Research in Ethics and Biomedicine and a Co-Director of the Quebec Network of Applied Genetic Medicine.

In October 2001 Dr. Knoppers received a Doctor of Laws *Honoris Causa* from the University of Waterloo and in December 2002 received a Doctor of Medicine *Honoris Causa* from Université de Paris V (René Descartes). In February 2002, she was elected Fellow of the American Association for the Advancement of Science and in May 2002 was named Officer of the Order of Canada and received the Queen's Jubilee Medal. She was selected among the 50 Nation Builders by the Globe and Mail for 2002. She founded the international Public Population Project in Genomics (P³G) in 2003. In that same year, she was elected Fellow of The Hastings Center (Bioethics), New York, member of the International Ethics Committee of the World Anti-Doping Agency (WADA) and in April 2005, was elected Fellow of the Canadian Academy of Health Sciences (CAHS) and Governor of the Quebec Bar Foundation. Professor Knoppers is the author of numerous articles and books.

THE 2006 KILLAM LECTURE

BIOTECHNOLOGY: THE HUMAN AS BIOLOGICAL RESOURCE?

NOVEMBER 2, 2006

PROFESSOR BARTHA MARIA KNOPPERS

“[P]ast restraint ... [on] the technological transformation of our genetic constitution ... has traditionally been seen as dependant on maintaining a fundamental difference between the natural and the artificial – a difference placed in question by modern technology.”¹

In 1992, the United Nations adopted what is known as the Rio Convention on Biological Diversity (CBD).² Since then, it has been ratified by 170 countries. The CBD defined biological resources as including genetic resources, organisms or parts thereof, populations, or any biotic component of ecosystems with actual or potential use or value for humanity. More specifically, it defined genetic material as any material of plant, animal, microbial or other origin containing functional units of heredity.³ It was not until 1995 that the CBD clarified that human genetic material was not included in this definition.⁴

The Organization for Economic Cooperation and Development (OECD) envisions biological resource centers (including human genetic material) as underpinning the future of life sciences and biotechnology.⁵ A draft guidance for such resource centers on the use of human-derived materials is currently out for comment. The proposed guidance states: “In the post-genomics era, human-derived biological resources for basic research use in general and

applied science constitute a strategic objective for (...) clinical, health-related biotechnologies and the development of new pharmaceuticals, medical devices, diagnostics and therapies”.⁶

In 2002, the Canadian Biotechnology Advisory Committee (CBAC) defined biotechnology as “a body of technical knowledge about living organisms or their constituent parts” without further distinction.⁷ Per capita, Canada has more biotechnology companies than any other country.⁸

The completion of the mapping of the human genome has confirmed our close genetic proximity to the mouse, the worm and yeast. Are we humans then, just another form of living matter, a biological resource that can serve to fuel the ever-expanding markets of biotechnology? Furthermore, will cyborgs and clones one day replace biological man with the post-human mechanical man?

Any response requires some understanding of actual and potential scientific “advances”. The human at the level of the species as well as that of the individual person, while in co-evolution and co-adaptation with nature, is more than the sum total of biological or prosthetic components. If so, are there socio-ethical and legal frameworks that protect and promote the human person as a member of humanity? To answer this question, I will illustrate in my first part how the scientific invention of the “post-human” is criticized in the debate based on three social representations: the natural order, species integrity, and the individuated self. These arguments however are inadequate as they are premised on a static view of Nature. In my second part, I will thus illustrate how the social reconstruction of humanity and so of the person, could be facilitated through the building of the concept of the common good. To do this, I will examine the notions of: common heritage; global public goods, and open science as a possible contribution to the development of the common good. In short, the issue before us is: “What are or could

be our biological and social geographies”? Our collective reply may well determine not only the future of the social contract but also that of the possibility of achieving global justice.

I: THE SCIENTIFIC INVENTION OF THE POSTHUMAN

The scientific invention of the posthuman is considered firstly as contrary to the natural order. It could be argued that in popular culture in spite of our “Pasteurian” knowledge about bacteria and of the life-saving power of blood transfusions, the modern Promethean image of the regenerative/replicable self began with the first heart transplant by Christian Barnard in 1974. Seen as the locus of the soul, this interference with the natural order was equated with “playing God”. The natural self under this school of thought holds the body as sacred in contrast with the non-human. “Removal of the idea that nature is a given, destroys the time-honoured belief that moral norms and standards exist outside of cultural prejudice and power plays. The elimination of the fact of a natural order, with all its imperfection and disappointment, erodes what tolerance is left for difference and unpredictability”.⁹ Today, Fukuyama epitomizes this approach; the essential human being is understood as a necessary reference point for the continuation of human experience and the construction of an ethical community.¹⁰ But the line between the human as a product of nature and that of *homo faber*, the human as a fabricator of nature is becoming blurred with the human as a fabrication of technology. Can we bear this moral burden of responsibility for the creation of a “second nature”, including our own?

Under the natural order, infertility treatment interferes with God’s will, with the notion of linearity in genealogy and with the genetic lottery. Permitting parental choices that include the timing of offspring, their source, their number and their quality is “unnatural”. Human nature is understood as pre-determined and static. Genetic engineering is anathetical to natural predetermined diversity. Para-

doxically, this position if taken to the extreme leaves the human person closer to the plant and animal species and the vagaries of natural selection and survival. Yet, it is supported by both the religious right and the eco-environmentalist left.¹¹ I would argue that we can make intelligent choices with regard to Nature. However, these choices should be based on a human conception of what is natural, not on a naturalistic definition of what is human.

Secondly, the argument in favor of species integrity is a logical extension of this first approach. In spite of having bred animals and hybridized plants for centuries, new possibilities such as xenotransplants (i.e. creating organs in animals compatible for transplant to humans) and the creation of chimeras (i.e. mixing materials from two or more organisms) are perceived as an affront to the hierarchical superiority and separateness of the human species. Yet, in the last decade, mice models have been created and used for the testing of human diseases.¹² Through recombinant research, genes can be spliced together from different species that would never be able to mate under normal non-laboratory circumstances.

The “yuk” factor also enters into play under this argument. There is an intuitive repugnance to the specter of genetically manipulated pig hearts or kidneys in humans. This is seen as diminishing our natural purity, superiority and sanctity. In the area of transgenic research, species integrity is understood as an impenetrable forbidding armour, even if safety could be ensured.

In 1998, biologist Stuart Newman and biotech critic Jeremy Rifkin applied for a fictitious patent for a “humanzee”, part human and part chimpanzee.¹³ This was a calculated move designed to re-ignite debate about the morality of patenting life forms and engineering human beings. The patent was denied by the US Patent and Trademark Office under the 13th Amendment of the Constitution forbidding slavery, that is, the ownership of another human being.

The USPTO did not define what was human and what was animal, however.

Animal welfare issues are important values but there is also an ethical imperative to do research on animal models where possible before turning to humans. If xenotransplantation is, after ethical and scientific review, thought “to be safe enough for human beings to pursue it as an option for organ procurement, then perhaps the ethical emphasis ought to be in carving out international standards for the way in which the pigs are treated in this transgenic science”.¹⁴ If safety is proven, familiarity and comfort with classical species categories is in itself insufficient to justify valuing and retaining such categories in the face of human suffering.

Furthermore, the United Nations Resolution called the *World Charter for Nature*, declares: “Every form of life is unique, warranting respect regardless of worth to man, and to accord other organisms such recognition, man must be guided by a moral code of action ...”.¹⁵ According to one author, a total split between personhood and animality would be false as it ignores the fact that our dignity is just the dignity of a certain sort of animal on a continuum of types of intelligence and of potential capacities.¹⁶

Human dignity then is at the core of species integrity concerns. What components or capabilities are so closely associated with human dignity that the development of human-nonhuman chimeras would violate it? Human capacities center on moral reasoning, acting on the basis of self-chosen purpose, complex communication and multifaceted social relations.¹⁷ These capacities are often associated exclusively with humans. Human dignity is inherent in the human person as person. A person with a pig heart valve, a pacemaker or prosthesis has never been considered less of a person in our society. What is inherent is inalterable and inalienable.

Thirdly, the most solidly anchored of all notions of humanness is that of the concept of the individuated self, the last bastion against the posthuman subject, as a collection of interchangeable components. If science can produce cyborgs and clones, what is distinctively human? The deliberate, external engineering of Life is seen as endangering the conscious, sentient mastery of the planet.¹⁸

Biology is information – both material and immaterial, transformed into technology. Ten years ago, the fear was of the geneticization of society, while now it is the fear of the technical re-design of life, the realization of the fictional X-Men.¹⁹ The issue here is the capacity through nanotechnologies or self-sourced stem cells to replace, slow down or impede defective or ailing bodily parts or functions. The notion of Man-Machine is seen as denying the uniqueness of the person. Like Prometheus, the regenerative and regenerated self is chained to the rock of scientific progress that does not allow us to die (or perhaps, the goal of regenerative medicine is to die healthy?). This instrumentalization or subjectification risks making us personally responsible for not preventing, avoiding or replacing. Such new forms of intervention as to the quality of life may well increase individual choice but also impose onerous responsibilities for the exercise of such choices, especially on women.

Power, as Foucault has argued, is now exercised at the level of life.²⁰ This allows individual control in the name of individual claims to a “right” to life, to health, to one’s body and to the satisfaction of one’s needs. Such individual vitalism can be exercised as a form of biopower. The current choices offered by preimplantation diagnosis of the embryo are a case in point. Newsweek reports:

“More than 3 million children worldwide have been born through in-vitro fertilization, but nearly 500,000 embryos have been rejected in the United States alone. The practice originally targeted fatal diseases, but now includes low-risk illnesses like arthritis. Others, such as leukemia, have no clear genetic cause,

and 42 percent of U.S. IVF clinics allow parents to select gender”.²¹

I would also ask: is this so different from germline modification that is currently prohibited? Germline modification would affect the reproductive cells so that deleterious genes are not passed on to the next generation. Yet, preimplantation diagnosis also prevents the transmission of recessive genes to the next generation. Ironically, at the same time, treatment of other conditions such as diabetes allows for the transmission of genes that a century ago would have been selected out since afflicted persons would die before reproducing.

The rhetoric of choice clearly resonates with the ethics of autonomy. Respect for autonomy was largely developed in the domain of research following the atrocities of World War II²² and in the clinical realm with the debate over brain death, euthanasia and the persistent vegetative state in the 1970’s.²³ It has spawned both laws and ethics frameworks where the individual and individual choice reigns supreme. Fears of designer babies have not materialized but the genomic and post-human management of the person and in turn that of the population may erase the actuality of individual embodiment, the possession of the body by its own being.

According to Rabinow and Rose, “[t]he stakes here are high, economically, medically and ethically. They lie in the presumed capacity of genomics to form a new ‘know how’ that will enable medicine to transform its basic logic from one based upon restoring the organic normativity lost in illness to one engaged in the molecular engineering of life itself”.²⁴ But the fear of slipping as a reason to halt genetic engineering is equivalent to denying afflicted individuals therapy on the grounds that humans cannot make distinctions as moral agents between the remedial and the eugenic. The problem may well be the locus of choice; it is perhaps

the collective “we” who in the name of individual rights have not had the courage to make the difficult choices.

In short, the prevailing ethos admires and supports the intellectual curiosity of each person to improve the frontiers and content of human nature. The individuated human self is protected through both laws and ethics. It could be argued then that both contemporary clinical ethics, research ethics and legislation, to say nothing of international norms that have promoted the overriding primacy of individual autonomy and privacy over the last quarter century, have indirectly favored the scientific invention of the post-human. To establish a degree of social control over genetic engineering, it will first be necessary to acknowledge that the principle of respect for individual autonomy is not absolute. Indeed, we need to re-ground our humanity in our sociality. We may need to socially reconstruct humanity in order to protect the person as human.

II: THE SOCIAL RECONSTRUCTION OF HUMANITY

Fifteen years ago, in 1991, Professor Claude Laberge and I published an article on “The Social Geography of Human Genome Mapping”.²⁵ We argued that genome mapping would allow us to demonstrate not only genetic diversity and individuality within a given biological family but also kinship, the interrelatedness of Man on this highly individualized and yet common map. We maintained that “[t]he social geography of the human genome is both collective and individual” and saw this project as a step in the recognition of the Family of Man. Yet, in 2003, the World Health Organization in a report on Genetic Databases: Assessing the Benefits and Impact on Human and Patient Rights stated that: “We have, then, a fundamental tension between the possibility of considerable public good on the one hand, and the potential for significant individual and familial harm on the other. The basic interests that lie in the balance are those between human dignity and human rights as against

public health, scientific progress and commercial interests in a free market”.²⁶In this second part, I will attempt to demonstrate that this is a false dichotomy, a facile polarizing dualism. Human dignity and human rights need not necessarily be set up against public health, scientific progress and commercial interests in a free market.

My attempt to socially reconstruct Humanity begins firstly with the recognition that “the universal basis of our common genetic heritage may serve to ensure the appreciation of its international nature and the avoidance of individualistic, property concepts”.²⁷ Secondly, I will examine another useful tool that has emerged from the environmental arena, that is, the concept of global public goods. Finally, I will conclude with an appeal for a return to the humanistic notion of open science.

The common heritage of Mankind draws its origins from the philosophy of Hugo Grotius. The legal criteria for the common heritage used for the open seas, for example, could also be applied to the human genome at the level of the species. The basic common factors of the common heritage of humanity concept are that: use of the information must be for the purposes consonant with peace; access must be open to those who have a right to it, while the rights of others must be respected (therefore, responsibility for abuse); sharing must be equal; and, owing to its indivisible character, the genetic heritage must be administered in the interests of all for the common good. This international concept stems from the need to prevent ownership of things of communal interest and to preserve things that are of international interest for future generations”.²⁸

This concept was integrated into article 1 of UNESCO’s 1997 Universal Declaration on the Human Genome and Human Rights²⁹ by the International Bioethics Committee. Political misunderstanding and wrangling over this precise legal concept, however, led to the adoption of a text that reduced the concept to a “symbolic” one and to the removal of the word “common”. The final version now

reads: “The human genome underlines the fundamental unity of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity”. Nevertheless, the common heritage of humanity remains as the bedrock of ethics for the Human Genome Organization (HUGO) in its Statements on Research, on DNA Sampling, on Cloning and on Benefit-sharing.³⁰

Recently, another concept has emerged, that of knowledge as a global public good. This came to the fore in the highly mediatic debate on global public justice in access to AIDS drugs by developing countries.³¹ It also has been instrumental in shaping the building and use of databases. The 2002 HUGO Statement on Human Genomic Databases held genomic population biobanks and the primary sequence data held therein to be global public goods. These goods are enjoyable by all without detriment to others. The recommendation reads as follows: “1. Human genomic databases are global public goods. (a) Knowledge useful to human health belongs to humanity. (b) Human genomic databases are a public resource. (c) All humans should share in and have access to the benefits of databases”.³²

“The language of global public goods is a strategic concept that argues for international collaboration in genomics research, and for global benefit-sharing of its results”.³³ It is crucial for harnessing genomic knowledge in a way that can contribute to health equity, especially among developing nations.

This collaborative approach has had some success with both the SNP Consortium and the international HapMap projects. The SNP Consortium was an initiative combining academia, foundations and pharma from five countries in a bid (a race?) to make the genome sequencing mapping effort an open and publicly accessible database. Data was released into the public domain every 48 hours.

The success of this pre-emptive, pre-competitive effort was such that the international HapMap completed in 2005 followed the same approach. Fears of parasitic patenting of the HapMap data led, however, to the creation of a click-wrap license subjecting access to the HapMap to recognition of its “public” nature. Most importantly, the results of the HapMap underscored the fundamental, biological unity of the Family of Man across different races.³⁴ This is not to say, however, that race is not a socio-political and economic concept with dire consequences, especially in access to health and opportunity.

The private sector then is beginning to recognize the need for international collaboration. Major pharmaceutical companies have recently created a CEO Roundtable on Cancer to break down the walls dividing the world’s major drug makers for an all-out effort against cancer. The Roundtable is considering a research plan to spread both the risks and rewards of drug discovery across a wide pool of companies so as to potentially speed treatments to patients.³⁵ The legal obstacles such as intellectual property rights and antitrust legislation are formidable.³⁶

Similarly, IBM announced on September 26th, 2006 that it will put its patent filings online as part of a new policy that the company hopes will be a model for others. In a press release it stated: “[T]he larger picture here is that intellectual property is crucial capital in a global knowledge economy. If you need a dozen lawyers involved every time you want to do something, it’s going to be a big barrier. We need to make sure that intellectual property is not used as a barrier to growth in the future. [...] The IBM policy seeks to address that problem, by taking a page from the open-source style of collaboration over the Internet. Just as open-source software is improved and debugged by a far-flung network of people looking at the code and spotting flaws, IBM hopes that a similar process can improve patent quality”.³⁷

Finally, underpinning this return to models of public values and the common good as a way of protecting and promoting the individual first and foremost as a citizen, is the notion of open science. It could be argued that today, this humanistic approach to science has been replaced by an econocentric one. Nevertheless, the concept of scientific progress has always been associated with the ideal of free and open dissemination of scientific knowledge.³⁸

Under the open science approach, the norm is one of common ownership of academic research results. This norm of “communism” or “communalism” — “[functions] together with other scientific cultural norms (universalism, disinterestedness, independence, invention, organized skepticism, etc.). It seeks to align the interests of individual scientists with the overarching institutional goals of scientific progress, defined as the extension of knowledge certified as true”.³⁹ According to the norm of “communalism”, scientific findings are a product of social collaboration, a common heritage that should be dedicated to the scientific community.⁴⁰ In light of this value of communality, “claiming property rights in inventions or keeping discoveries secret [is] perceived as immoral”.⁴¹

An example of an open-science initiative is the Public Population Project in Genomics (P3G). Its mission is to: “facilitate the sharing of expertise and catalyze efforts to develop research strategies and tools for a meaningful collaboration between biobanks, and to disseminate this knowledge in the public domain so as to support the international scientific community in improving the health of populations”.⁴² To date, 17 large-scale population studies have agreed to participate in the public interest. Membership spans 27 countries. The concept is not to create an international meta-database or Biobank but to share research tools, to create a lexicon and to formulate guiding ethical principles so that the results can be validated around the world and the products of such research on common diseases will become more readily available.

Population biobanks are longitudinal studies that seek to understand the role of gene-gene and gene-environment interactions in multifactorial conditions such as diabetes, cancer, hypertension and asthma. Public investment and public trust are enormous. The United Kingdom's Biobank alone is studying 500,000 individuals. Here in Quebec, CARTaGENE⁴³ is proposing to study 20,000 persons aged 40-69 in its first five years and then 30,000 aged 25-40 – both groups together over a span of 50 years!

In this same vein, arguments are emerging that liken this donation of genetic samples and demographic and lifestyle information to population biobanks for longitudinal studies as a donation to a public biotrust. The key benefit of this public, fiduciary model is both the fact that the collection must be managed for the public benefit and that it has a recognized governance architecture. “In its ideal form, this architecture would help foster a Habermasian space for public deliberation and learning ... [In this way,] we can recreate genomics as an enterprise driven not by profit, but by collective political will”.⁴⁴

What then are the implications of this “common good” approach for biotechnology? To return to the beginning of my presentation, the view of biological resources whether animal, plant or human as under individual control and as an individual human right has actually harmed the countries who ascribed to it under the 1992 Rio Convention. Indeed, by discarding the “common heritage” concept to embrace state sovereignty so as to allow states to contract or to legislate ownership of genetic resources, the effect was an increase in intellectual property rights and a decline in exchange and minimal benefits for farmers.⁴⁵

Thus it was necessary in 2004, to adopt the United Nations, International Treaty on Plant Genetic Resources for Food Agriculture.⁴⁶ This Treaty facilitates access and benefit-sharing, reduces transac-

tion costs and reinstates some aspects of common access and use. Broad humanitarian licensing is envisaged as well as open-source strategies.⁴⁷ I would argue that a new global regime is also required in the health sector so as to respect human rights and public health priorities. Both public access and private innovation are needed to stimulate Research & Development (R&D) with equitable outcomes. A Global Framework on Essential Health Research and Development is being proposed.⁴⁸ Likewise, there is a move in academia to promote equal access to university research.⁴⁹ In short, control is a double-edged sword.

CONCLUSION

In conclusion, humans hold a special place in nature. Apocalyptic views on biocolonialism, the “order” of Nature, chimeras and genetic engineering should not detract from the fact that medical research is a public good. All of us as individuals, as members of families and of society have benefited from those who participated in research in the past.⁵⁰ Public trust, public participation in research and in common good endeavours however require clear stewardship, transparent and accountable oversight, and ongoing monitoring.

Re-characterizing fundamental biological data as a public resource so as to socially re-humanize the person and have some measure of social control over rampant individuality will not be simple or free from other risks, largely political. It also requires “an ethical duty to work toward a just distribution of the benefits of such research, both financial and therapeutic. Without some symmetry between the burdens and the benefits of research, the social compact underlying such an imposition on personal interests would be undermined”.⁵¹

We must seek “the elusive balance between respecting the dignity of human persons and generating public value, a balance that has been unsettled by the new modalities of biological science technology and property”.⁵² We need acknowledgment of human complexity and finitude and a determination to resolve problems by means that realize human integrity, not undermine it. The greatest threat to humanity is both the absence of recognition of science and of the “Family of Man”. We are all the children of “homo sapiens” who came out of Africa 100,000 years ago even though we do not speak the same language, have the same culture or religion and do not look alike.

It is only through an attachment to justice and to the spirit of co-operation in our biological and social geographies, that the dignity and well-being of persons both as individuals and as world citizens can be promoted. The task is to avoid dualisms and polemic that ultimately derail the possibility of increased public debate and harm both the individual as person and as citizen. In short, we need to ground our personal humanity in our sociality. We cannot scientifically invent the human but we can foster the common good so as to ensure the humanity of each person.

* The author would like to thank Yann Joly from the Centre de recherche en droit public of the Université de Montréal for his assistance with the manuscript.

1 BAILLIE, H.W. & T.K. CASEY, eds., *Is Human Nature Obsolete?* (Cambridge: MIT Press, 2005) at 7.

2 Convention on Biological Diversity, 5 June 1992, 30619 U.N.T.S 143.

3 Ibid., at. 2.

4 *Convention on Biological Diversity, Conference of the Parties to the Convention on Biological Diversity. Second meeting (1995) Decision III/11- Access to Genetic Resources.* paragraph 2. ‘[The Conference of the Parties] [r]eaffirms that human genetic resources are not included within the framework of the Convention’.

- ⁵ Organisation for Economic Co-operation and Development, *Biological Resource Centers: Underpinning the Future of Life Sciences and Biotechnology* (Paris: OECD, 2001).
- ⁶ Organisation for Economic Co-operation and Development, *Draft Guidance on the Use of Human Derived Materials* (Paris: OECD, 2006) par 4.
- ⁷ Canadian Biotechnology Advisory Committee, *Patenting of Higher Life Forms* (Ottawa: CBAC, 2002) at 1.
- ⁸ *Ibid.*
- ⁹ ELSHTAIN, J.B., “The Body and the Quest for Control” in *Is Human Nature Obsolete?*, *supra*, note 1.
- ¹⁰ FUKUYAMA, F., *Our Post-Human Future: Consequences of the Biotechnology Revolution* (New York: Farrar, Straus and Giroux, 2002).
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