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EUGENICS: THE (UN)ETHICAL TRUMP CARD?

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It is with some trepidation and humility that I address you today - a former scholar of poetry, a social scientist, a law professor "reborn" as a Professor of Medicine at the Department of Human Genetics in the Faculty of Medicine of McGill University. The quixotic nature of the subject of eugenics of the Galton lecture which you have asked me to address is best suited for a true genetic scientist. Yet, I feel privileged to exploit my eclectic career to perhaps bring a more citizen-oriented perspective. The main purpose of my lecture is to argue, if not to plead, for an end to the label of historically-laden terms such as "eugenic" as an (un)ethical trump card thereby either enflaming, if not stopping, all public debate. So laden with socio-ethical and legal import, this concept should not be trivialized or cheapened especially in public debates where like Jungian archetypes it stirs the collective un??conscience.

Surrealist poetry, where I began my academic pursuits, was a tool to break free from the conventional norms imposed by tradition. Both painters such as Salvador Dali and poets such as André Breton juxtaposed non-connected ideas, objects, words and images in order to break free from convention to explore, understand or portray new visions of reality.

The political realities of the 70's however, led me to forsake my doctorate in literature comparing the power of this surrealist revolution in Caribbean poetry with that of Quebec, for the more politically active discipline of law. If law is seen as a tool for social reform and justice, why not examine its potential to respond to emerging technologies that affect humans and humanity at the most intimate of all levels – that of human reproduction and genetic choice?

To address the most obvious arguments (or rather, reactions, such as "playing God", "slippery slope", "unnatural", and, "eugenic") that came to the fore in public discourse with the in vitro fertilization assisted birth of Louise Brown in 1978, I have divided my presentation into four parts covering the four decades since her birth. I will conclude with some thoughts on the potential role of human rights to enrich the debate on eugenics with the arrival of gene editing.

But as preamble, and true to a lawyer's insistence on definitions, a brief "definitional" scoping exercise.

Let's begin with the present. In her book, The New Genetics: Selective Breeding in an Era of Reproductive Technologies[1], Judith Daar presents what she calls the "new eugenics" in relation to Assisted Reproduction Technologies (ART). She defines the new eugenics as "collective procreative deprivation", or, "selective breeding". This is due to the lack of affordability and availability, and to the discretionary withholding of ART from the less wealthy, less white, less

able-bodied, less traditional and less politically wealthy. Her novel insights and recommendations for the democratization of ART through greater availability and accessibility add fuel to my conclusion on the hitherto unexplored avenues of human rights in the debate on eugenics in reproductive medicine and genetics.

Other more well-known definitions merit mention here as well. Eugenics as procreative beneficence, a form of liberal eugenics or neo-eugenics, allowing parents via autonomous choices to maximize the well-being of their future children through pre-implantation and prenatal selection or through gene enhancement therapies for children – the sum total of voluntary improvement of the human race at the individual level of procreative choice.[2]

The more classical forms of definitions of eugenics date back to the negative eugenics of the Nazi legacy through the prevention of the reproduction of the unfit, or, positive eugenics defined as improvement of the inborn qualities, or stock of a race or population and even dysgenics, that of racial degeneration, a modern example being the survival and reproduction of those who would have died or been selected out due to disease but now can reproduce thanks to medical treatment (e.g. diabetes). Sir Robert Edwards, the pioneer of in vitro fertilisation (IVF) was himself a member of the Eugenics Society in Britain. His IVF technique is responsible for the birth of over 5 million children worldwide and, it is with him that our four decades journey begins.

I. From Bio-Identity to the Genetic-Self (1975-1985)

In 1979, I had the privilege of interviewing Robert Edwards while studying at Trinity College at Cambridge University here in the UK. If ever there were scientists under attack for playing with the so-called immutable laws of nature, for playing God, by creating "designer babies", Steptoe and Edwards were the target. Thirty years out from the horrors of the Nazi experiments and barely rid of the last forced sterilization laws that still lingered in the early 70's even in Sweden and Canada, the label of eugenics weighed heavily on IVF as did the specter of human reproductive cloning. At that time, work on my doctoral thesis on reproductive technologies sought to prepare physicians and researchers for these new responsibilities.

Gracious and giving of their time to a mere student (a model I have tried to emulate), Steptoe and Edwards were forthcoming about their own fears and pressures of failures and outcomes, even after the success of IVF, while very passionate about helping infertile couples. In industrialized countries, unbeknownst to most – since often a hidden stigma – involuntary infertility is at 16% in persons of reproductive age. Today, IVF for genetic indications would be about 10% of all IVF treatments.[3]

In 1984, the UK Warnock Commission Report adopted what is commonly known as a "pragmatic and principled approach" leading to the 1990 Human Fertilisation and Embryology Act[4] and the creation of a regulatory agency, the Human Fertility and Embryology Agency (HFEA). Other countries left IVF to professional guidelines and strictly curtailed embryo research. Germany for example, adopted the Embryo Protection Act[5] in 1990 and the National Institutes of Health (NIH) adopted a no-federal-funding of embryo research model. Paradoxically by removing federal funding it abandoned oversight and the private sector largely took over in the

US. Moreover, technology specific legislation on reproductive and genetic choice adopted in different countries often had the perverse effect of creating IVF tourism or led to scientists continuing to work around the arbitrary limits of quickly outdated definitions of when human life began.

It should also be remembered that the deterministic, single-gene Mendelian model of human genetics was greatly influential at that time – one's genome being understood as a blueprint, the book of life. In addition, in the 1980's, the larger issue of reproductive choice including prenatal decisions and abortion also influenced the contours of IVF acceptability in health care systems. So pervasive and inflammatory was the dogma of non-interference with the human genome seen as static, as genetically pre-destined, that 25 years later the 2005 debate at the United Nations on human reproductive cloning did not achieve sufficient consensus to go beyond a simple Declaration on Human Cloning[6].

Not to be forgotten was the emergence of sociobiology as espoused by Wilson in the late 70's. Sociobiology which promoted the concept that social behaviors are biologically influenced, encoded within our genes, and shaped by the forces of evolution. Biosocial science prompted the American Eugenics Society to change its name to the Society for the Study of Social Biology. Stephen Jay Gould and Robert Lewontin were quick to qualify this field as biologically deterministic and as perpetuating "eugenic ideologies that sought to legitimize racial and social hierarchies".[7]

The decade of 1975-85 also witnessed the attempt to promote property approaches for genetic materials via patenting claims and notions of personal ownership of genetic data. Thus, while marked by the novelty of IVF, by the women's reproductive rights Roe v. Wade[8] abortion decision in the USA and by the arrival of genetic testing in the prenatal arena via amniocentesis, the decade following the IVF "creation of human" life in the laboratory can best be described as a debate on bio-identity – on the genetic self.

II. From Population Genomics to the Commons (1985-1995)

Turning to the decade of 1985-1995, it is often forgotten that genetics even then was already enshrined in public health since the 60's in the form of newborn screening. Even today, these programs are seen as "one of the ten most important public health achievements".[9] Until recently, to qualify as genetic screening that is, a test to be administered across an asymptomatic population to find at-risk individuals for diagnosis and treatment, four WHO criteria had to be fulfilled. The criteria to be met were: 1) an important health problem; 2) a test with sufficient sensitivity and specificity; 3) acceptable costs; and, 4) the condition had to be immediately treatable.[10] Long deemed as in the best interests of the newborn, these programs are now facing the possible introduction of whole genome sequencing as a new screening tool.

Population genomics and interest in human diversity appeared just as the human genome project took off in these early 1990's. Indeed, the decade of 1985-1995 was characterized by this most ambitious international endeavour. As Chair of the international ethics committee of the newly created Human Genome Organization (HUGO)[11], the question was how to foster "The

Principled Conduct of Genetic Research".[12] All HUGO guidance for the next 20 years attempted to address concerns that:

- […] genome research could lead to discrimination against and stigmatization of individuals and populations and be misused to promote racism;
- Loss of access to discoveries for research purposes especially through patenting and commercialization;
- Reduction of human beings to their DNA sequences and attribution of social and other human problems to genetic causes;
- Lack of respect for the values, traditions, and integrity of populations, families, and individuals; and;
- Inadequate engagement of the scientific community with the public in the planning and conduct of genetic research.

More importantly, such guidance was founded on: the recognition of the human genome as part of the common heritage of humanity; adherence to international norms of human rights; respect for the values, traditions, culture, and integrity of participants; and the acceptance, and upholding of human dignity and freedom.

One of the most enduring legacies of this project to sequence the human genome was the creation of the SNP Consortium that, in contrast to a privately-funded sequencing endeavour[13], put all its international data in the public domain. This notion of building a "commons" of data was exemplified in HUGO's Bermuda Principles on intellectual property.

The ideal of the human genome as the common heritage of humanity finds its origins in the principle of international law first espoused by Hugo Grotius and underlying the law of the sea and of space. Its components are: utilization must be peaceful; access must be open; sharing must be equal, and, administration be in the interest of the common welfare. "[This] international concept stems from the need to prevent the private ownership of things of communal interest and to preserve for the future things that are of international interest – a form of "public trust".[14]

It should also be mentioned that this decade witnessed the arrival of wrongful birth and wrongful life cases. The first taken by parents claiming that but for the negligence of the physician, the child with a genetic condition would not have been conceived or allowed to go to term while the second, taken by the child, claimed that but for the negligence of the physician he or she would not have been conceived at all. Some of these cases were successful, usually the parental wrongful birth suits in the situation of proven genetic malpractice. The wrongful life cases however have rarely succeeded, the rationale being that it is impossible to measure the impaired existence of a child against non-existence as the child would not exist at all, and this even in the presence of proven fault. Interestingly, countries such as France and the UK both legislated that children could not sue their mothers for reproductive, genetic choices.

Finally, the discovery of the gene for Huntington's chorea in 1992 sparked anew the debate on possible genetic discrimination in insurance and on "predictive" medicine and possible

familial obligations to warn – debates that continue today. Another landmark, if not iconic event however, was the reproductive cloning of "viable offspring derived from fetal and adult mammalian cells"[15] – that is, the birth of Dolly, the first cloned mammal. Again, I had the privilege of interviewing Ian Wilmut, a most self-effacing and forthright researcher, quite unprepared for the tumult that followed. So notorious was Dolly, that perhaps more than Louise Brown, she entered into popular culture. Finally, the early Star Wars series with its morality dilemmas, the claims of the Raelians of possible human reproductive cloning, and later the movie GATTACA, imprinted the potentially dire consequence of genetic manipulation into the human psyche during this second decade.

III. From Privacy to Digital Identity (1995-2005)

As mentioned, early data disclosure and release were the hallmarks of the HGP. Genome-wide association studies and genome sequencing became the new tools for data mining. Importantly, the focus shifted to understanding the common variants underlying complex diseases on the networks of pathways contributing to disease risk, susceptibility and health. The genetic-self in the genome commons was thereby expanded to include the quantified, the digital-self.[16] As the sequencing map of the human genome was completed in 2003, attention began to turn to applying this map, to finding "addresses" for the sequences, that is, to gather the data needed to understand what the sequences were saying.

Data intensive science in this third decade, however, was not without its detractors creating barriers to building the infrastructure necessary to support discovery science. The planning began for the building of population cohort biobanks and databases as representative of a given heterogeneous population such as the UK Biobank and the Estonian biobank. As mentioned, such endeavours hoped to serve as a form of infrastructure science for discovery science. In these epidemiological efforts, participants would be acting as longitudinal citizens providing data and samples over time with no immediate personal benefit.

Ethics committees however were accustomed to clinical trial requests with their attendant interventionist dangers of drugs and devices and often applied ultra-protectionist, inappropriate risk-benefit standards to the ethics review of such biobanks. Moreover, it proved difficult to replace specific consent with a broad consent to participation in biobanks and population databases for future unspecified research with ethics approval. Specific, limited consent had been a sine qua non since the Nuremberg Code[17] and the Helsinki Declaration[18]. Yet, for these efforts to succeed, data could not be specific, anonymized, or limited in time, as longitudinal biobanking meant just that, following people in real time, over time, across different environments and socio-economic and demographic conditions thereby requiring ethics approval for future, unspecified research. Respect for autonomy and privacy were seemingly put in jeopardy. In addition to ongoing ethics oversight over broad consent, privacy was also sufficiently protected. The European Privacy Directive on the protection of individuals with regard to the processing of personal data and on the free movement of such data of 1995 for example[19] required proof of equivalency of privacy protections in order to share data within and outside of Europe.

Citizens however understood this new form of infrastructure science and accepted broad consents to future, unspecified approved research. Such population genomic data held the promise of stratification into sub-populations for targeted resource allocation by Ministries of Health. In the rare disease community, patients began to advocate for more data-sharing and access and this across borders. Yet, again individualistic, specific consent requirements or over-protectionist privacy policies based on hypothetical "what-if-some-day" re-identification scenarios often blocked approval. It was some time before proof of a "reasonable likelihood" of re-identification, of data breach or of misuse was adopted, a more proportionate approach than zero tolerance based on hypothetical risk. Patient engagement also grew as patents were sought by rare disease groups themselves and websites sprung up dedicated to sharing information, the patient as partner, and the citizen as participant. PatientsLikeMe exemplified this dynamic and interactive approach to genetic research and medical care.

This road to citizen science, to data access and sharing was not an easy one. P3G (the Public Population Project in Genomics and Society) was founded in 2003 to prospectively ensure as much as possible future interoperability between biobanks and databases around the world so as to maximise statistical significance.[20] Locally, CARTaGENE[21], Quebec's population cohort, required convincing 18 ethics committees not all of whom agreed.

The notion of a "genomic" plus "population" study using public funds and creating a resource representative of a given population for future clinical research was considered both too novel and too dangerous, the Quebec ethics committees fearing both a hidden eugenic agenda and the possible revelation of unwanted genetic secrets, the data themselves being capable of recreating the digital genetic self. Ultimately, CARTaGENE however had the highest collaboration rate of citizens (23%) of any national biobank in the world. Finally, what remained the biggest challenge however was not the politics or the ethics but rather coming to an understanding and appreciation of the complexity of common diseases. Positive, predictive value was often uncertain, understanding of susceptibility and probabilities was influenced by multiple socio-economic and environmental factors and only a few pharmacogenomic drugs or treatments emerged. Furthermore, how to communicate genetic risk, genetic probabilities, as opposed to genetic certainties?

IV. From Gene Editing to Enhancement (2005-2015)

The recent 2015 gene editing breakthrough of the year in Science was preceded by a fourth decade of incremental but noteworthy, emerging technologies, emphasizing and expanding once again individual genetic choice. The sum total of such choices illustrates a shift in their social acceptability. Indeed, non-invasive fetal cell sorting and embryo selection with pre-implantation genetic testing of embryos like prenatal testing it largely placed such genetic choices out of the public eye into the privacy of the physician-patient relationship.

The logic of this freedom of reproductive and genetic choice was of course underpinned by the concomitant expansion of freedom of abortion and reproductive choice. In the absence of specific reprotech legislation or professional guidance on clinical choices, would the same

range of freedom of reproductive choice now logically apply to embryo selection as it had to prenatal choices?

Two other scientific "innovations" contributed to challenge the logic of new emerging, pre and post-natal "quality of life" choices. The first was the possibility of enhancement especially as concerns gene therapies in, for example, the growth of muscle mass and the second, the arrival of epigenetics. The former is still largely limited to animal models but merits further scrutiny especially as concerns the rights of children and the second is definitely a game changer.

Epigenetics involves understanding the basic mechanisms of cell differentiation and cell identity but today the emphasis is on environmental epigenetics[22] and so may revert us back to sociobiology, if not notions of "acquired heredity". Moreover, a "deterministic reading of epigenetics … may create the impression that individuals, their health and their behaviour are bound and ruled by the epigenetic marks they have acquired in early life" thereby ignoring social conditions. Indeed, "[a] failure to acknowledge the greater complexity of social life might lead environmental epigenetics to contribute, possibly unwittingly, to perspectives that frame poverty and social disadvantage as something that "replicates itself from generation to generation".[23]

Also, in 2015, the arrival of CRISPR gene editing left the policy world gasping for air. This is due in part to the fact that criminal bans on genetic modification over 20 years ago foreclosed what should have been ongoing debate since politicians and the public were mollified and appeased, thinking the issue had been settled. Today, the CRISPR debate is dominated by metaphors that reduce complexity and exaggerate control of outcomes. For teaching purposes, I have catalogued the most popular ones used on the covers of established and recognized journals and reviews in 2015: engineer, exterminate, ethics, edit, eradicate, erase, evolution, enhancement, experiment and eliminate:

> "We need metaphors for CRISPR that indicate the technology's uncertainties and unknowns, and that convey its current value to basic research and potential clinical and public health benefits. (…) [But], metaphors should accurately represent how the technology actually works and can be used, should avoid reductionist effects, and should allow for understanding of bioethical implications."[24]

While today the potential and value of somatic gene therapies affecting only the individual is beginning to be approved and recognized, in December 2016 an International Summit proclaimed germline modifications that is, affecting descendants, as "irresponsible". Yet, three months later, the US National Academies recommended that germline genome editing trials be permitted under very strict conditions and oversight.[25] In July 2017, 11 genetic expert societies joined the American Society of Human Genetics in its Statement on Human Germline Genome Editing[26] also cautiously allowing germline editing research. This fall, the European Society of Human Genetics and the European Society of Human Reproduction and Embryology also approved both basic and preclinical research regarding germline editing in the situation of the transmission of high risk of serious disease (personal communication). Moreover, if the research question cannot be adequately answered on the basis of spare embryos alone, provided

that research embryos are necessary to reach the aim(s) of scientifically sound and robust research, deliberately created embryos could be used as well. Yet, will such pre-implantation research and selection obviate the need for germline modification in adults as a form of "therapy"? The professional policy roadmap is seemingly coming to some form of cautious consensus. At the 20th anniversary of the Council of Europe's Convention on Human Rights and Biomedicine (Oveido Convention)[27] in Strasbourg on October 24-25th of this year, there were also calls to revisit the ban on germline modification research but they were quickly refuted by its Parliamentary Assembly. Likewise, a recent landmark Lancet article on "Stem Cells and Regenerative Medicine" has argued that the lack of effective global governance, particularly over unproven stem cell "therapies", needs to be remedied with more regulation, not less.[28] Indeed, the recent convergence of stem cell and genomic research into what might be called "cellular genomics" bears close watching.

Conclusion: From Bioethics to Human Rights:

Will then the incipient, liberal, neo-eugenics of choice or the emerging new economic eugenics hold sway? My first immediate answer would be that of my introduction. The judicious use of this provocative term does serve to remind us of past, present and future dangers of the effects of untrammeled political state programmes or individual choice. The Nuremberg Code, bioethics frameworks, professional self-regulation via guidance and State intervention via legislation have shaped and continue to shape the trajectory of reproductive and genetic choices. Gene editing however, is forcing the topography of past and present "eugenic" choices into the limelight. How then to take current regulatory approaches and reshape them into more compelling and global frameworks?

I maintain that in complement to the bioethics frameworks and laws, it is time to activate a human right that has hitherto lay largely dormant – the right of everyone "to share in scientific advancement and its benefits". This human "right to science" has its origin in the 1948, Universal Declaration of Human Rights[29] and was made legally binding under the International Covenant on Economic, Social and Cultural Rights (ICESCR)[30] of 1966, since signed and ratified by 165 countries.

Because of its public international law status, the content of this human right has universal force and its legal "actionability" can reach beyond the moral appeals of bioethics. It imposes positive duties on States who are accountable to their citizens to respect and uphold this right. Until now there have been limited efforts to develop the content of this right to science. In the context of biomedical and genetic research, it can also build on the jurisprudence of other human rights such as those of health, to procedural fairness, anti-discrimination, equitable access to medical care, and privacy.

Since the Nuremberg Code, the goal of bioethics in biomedical research is understood as protecting the research participant, formerly named the research subject. The activation of this human right to benefit from science and its applications would harness bioethics principles to also promote human health and not just focus on the potential or hypothetical harms of research.

Perhaps, the most immediate realization of this right to benefit from science and its applications would be through the acceleration of international data sharing and of open science. While article 27 of the Universal Declaration of Human Rights and its counterpart in the ICESCR also recognize the right of innovators and of creators to be recognized for their work (right of attribution/intellectual property), its translation into a duty to share a minimal set of medical data, especially in the healthcare sector, could radically transform healthcare from a systems point of view. Indeed, research and medical care could be joined in feedback loops of data into a learning healthcare system with minimal risk and improved research based care. Enabling big data moreover, will also play a role in ensuring the survival of accessible and affordable care via targeted allocation of resources at the level of health care systems and public health. Medical care for modern heterogeneous populations requires data from diverse populations around the world. It is more data not less that will help us understand the scientific "irrationality" and futility of positive and negative eugenics.

How then to combat simplistic, linear approaches to policymaking and the use of debate-killing terms such as "eugenics"?[31] The answer is probably as complex as human genetics itself. One month ago, I was in Strasbourg at the Council of Europe. The goal of this Council of Europe meeting in Strasbourg was to both celebrate and revisit the 1997 Oveido Convention after 20 years. Fundamental questions were raised: Does genetic exceptionalism in the form of genetic-specific laws contribute to and exacerbate stigmatization rather than prevent genetic discrimination now that we know that genetic factors play a role in most common diseases? Can gene editing serve to alleviate the human burden of severe, incurable conditions? Should the Oveido ban on gene modification in descendants be lifted?

International policymaking is messy, slow and arduous.[32] At this meeting in Strasbourg, the bittersweet nature of believing that persons are fundamentally good came to life in the surreal spectacle of watching Italian soccer players come onto the field against their right wing fans by wearing tee-shirts with the photo of Anne Frank. They asked for a minute of silence while reading aloud from her diary citing her: *"… I somehow feel that everything will change for the better, that this cruelty too shall end …"*. A diary, the faith of a young Jewish girl in hiding and the mass message of hope in humanity were juxtaposed into a living surreal demonstration of the power of fighting racist, if not "eugenic" ideologies of soccer fans.

So we return to where we began. My lost doctoral thesis on surrealist poetry hypothesized that the literature of suppressed, colonized peoples began by poets and artists outperforming their master's in their own art form, then revolting via surrealist techniques to return to local, indigenous lost forms of expression, to finally moving past such protest literature to more personal introspection and forms of expression. Ironically, the more highly personal the art form became, the more universal it became, as illustrated by the work of Derek Walcott, the Caribbean poet who was awarded to Nobel Prize for literature in 1992, and who died earlier this year.

Is this the route for medical genetics as it moves from Mendelian, to the genomes of diverse populations, to personalized precision medicine? If so, the true appreciation of human

diversity resides not in the sequence maps or notions of races and populations nor even illusions of equality but rather in appreciation of difference and of equivalence in risk. Variants are not mutations. Will the flood of knowledge on genome variation and the elasticity of their classification over time lead to an appreciation of difference as an indicator of health and of resistance as much as of probabilistic susceptibility to disease? If so, the "social control" of eugenics is sure to be defeated by the very complexity and individuality of human life contributing to the "genetic makeup" of not just a family, or, a population, but of the human genome, that is, humanity. Advantage comes from adaptation and from preserving diversity and difference within a social fabric that cultivates and supports equality of opportunity while recognizing equivalence in difference. This however, does not preclude saving children from being afflicted with serious genetic conditions.[33]

It is axiomatic that with the recent Anne Frank story we return to the classical definition of eugenics, that of Francis Galton himself: "Eugenics is the science which deals with all influences that improve the inborn qualities of a race; also with those that develop them to the utmost advantage."[34] Anne Frank died in Bergen-Belsen. One of my Dutch aunts who was Jewish lost all the members of her family in Bergen-Belsen and she herself was sterilized. Hence, my personal aversion to the liberal use of the term eugenics in debate as an unethical trump card.

Irrespective, while one could argue that untrammelled individual procreative and genetic choices constitute a disguised, hidden form of incipient and insidious eugenics, I think we should reserve the term for State programmatic actions or inactions in terms of ensuring the quality and safety of the science behind the difficult and complex social and personal decisions that lie behind individual and parental choices and especially, the oversight, or lack thereof, by professional medical societies and healthcare systems.

> Russell Powell argues:
> "[…] it remains an open question whether on balance the risk of repeating [past] moral failures outweigh the benefits to be obtained and injustices to be avoided by engaging in the large-scale modification of the human genome. Even if morality demands that we make germline modification technologies available to healthcare consumers, and even if parents have a moral obligation to avoid creating offspring with avoidable gene-based diseases, it is an entirely separate ethical question whether this obligation should ever be coercively enforced by the state."[35]

While agreeing with the latter part of this quote as concerns State eugenics, procreative beneficence with its obligation on parents to provide the child with the "best life" in the form of dubious enhancements, is not the same as preventing harm to children in the case of severe diseases[36], and even then, it would at most be a personal and free moral choice, not a legal obligation.[37]

I would argue not for the creation or imposition of legal obligations or genetic rights but rather more international data sharing, more knowledge on individual and populational complexity and thus, a greater appreciation of difference. Today, in genetics, "information is

often THE treatment" and will be so for some time as we try to develop gene therapies for debilitating human diseases.

> Finally, as I wrote in 1991:
> "[…] the education and participation of medical practitioners and of the public are crucial. Such education and participation will serve to situate the locus of the communication and control of individual choices in genetic medicine, not in the molecular biology laboratory but in the physician-patient relationship. This relationship is the ultimate insurance against state eugenics and against the emergence of the language of 'genetic rights'. Only then will the equation between genetic revelation and apocalypse, between genetic information and discrimination, between the person and the disease, be erased."[38]

To conclude, I cite from "Morning, Paramin" Derek Walcott's last book:[39]

"… Everywhere is wrong
as all forms miss perfection, hence the mask
in which the whole society is based."

Eugenics is about perfecting human life and therefore "wrong". True appreciation of the complexity and adaptation of humans and humanity defies attaining such perfection.

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