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Prenatal Cystic Fibrosis Screening and the New Eugenics
A Need for a Moratorium

Abstract

Prenatal cystic fibrosis (CF) screening is quickly becoming the standard of care for pregnant women. There has been insufficient ethical reflection in the literature on the implications of such screening. Papers addressing the topic have focused solely on the issue of informed consent and reproductive autonomy. Inadequate informed consent is likely occurring due to the uncertainties of prognosis of an unborn child diagnosed with CF. The eugenic nature of testing, the social pressures to undergo testing and the discrimination that will result need further consideration. A moratorium on prenatal CF testing is strongly recommended.

Key Words

"Cystic Fibrosis;" "prenatal screening," eugenics, testing, moratorium

Introduction

In 1999 the National Institutes of Health (NIH) published a consensus panel statement to provide health care providers, patients and the general public a "responsible assessment of the optimal practices for genetic testing for cystic fibrosis (CF)." The stated goal was to "provide individuals with information that will permit them to make informed decisions." [1]

The recommendations from the expert panel were the following: CF testing should be offered to adults with a family history of CF, to partners of people with CF, to couples currently planning a pregnancy, and to couples seeking prenatal care.

Following the lead of the NIH, in 2001 the American College of Obstetrics and Gynecology (ACOG) published their own set of recommendations and distributed a packet of guidelines and educational documents. The materials were intended to educate providers and patients on CF screening. ACOG's recommendations were similar to the NIH statement with the exception of placing a greater emphasis on offering CF testing for Caucasian couples. They are the patient group at highest risk for being a carrier for the gene mutations that cause CF.

In practice the patient population that has been targeted for screening is women seeking prenatal care. Since the publication of ACOG's guidelines, the rate of prenatal screening for CF has increased precipitously.[2] CF testing is joining the quadruple screen, which screens for chromosomal abnormalities (Down Syndrome in particular) and neural tube defects, as another "quality control" test offered to women. The intent of such testing is to screen for conditions affecting the unborn child. The marketing of the tests and the studies supporting their implementation clearly have selective abortion in mind as the intended use.[3]

As discoveries from the Human Genome Project (HGP) continue to unfold, there will be an increasing number of genetic tests offered to women seeking prenatal care. CF testing has been regarded by the Center for Disease Control and Prevention (CDC) as a "paradigm for public health genetics policy development."[4] The CDC's focus when publishing this policy statement was newborn screening. Nevertheless, the test is

quickly becoming a part of prenatal care. As more genetic tests become available, it appears conventional wisdom is dictating that these tests will be offered to pregnant women as well.

Prenatal CF testing is complicated and problematic at several levels and raises multiple questions. CF and the antenatal testing for it are extremely complex processes. There is significant uncertainty in the meaning of the diagnosis, if it is made antenatally. Is it possible to conscientiously educate patients of the complexities and uncertainties of testing to an extent where potential harm will not occur?

There is concern that CF screening is another test that women will be pressured to have performed. Is nondirective genetic counseling a real process, or is it a myth?

Prenatal screening and elective abortion of "defective" children is inherently eugenic in nature. Is an era of new eugenics being ushered into society on the heels of the eugenic movement of the 20th century? Have we as a society learned from our previous mistakes of inhumanity?

Discrimination is already occurring to families caring for children with Down Syndrome.[5] Can the medical community and society ensure that economic and social discrimination will not occur if the mother chooses not to abort her child with CF?

As the list of tests continues to grow, the list of unborn humans that will be deemed unfit for life will also continue to grow. Are there any criteria that could be used to decide what level of fitness is required for entrance into the world? As prenatal quality control measures increase, are we as a society making our children commodities to be conditionally accepted versus gifts to be unconditionally loved?

Finally, as we continue to gain greater control over prenatal life, is there actually a loss of freedom occurring? Is prenatal diagnosis with its inherent pressures simply giving an illusion of choice? In our efforts for quality control are we ourselves being controlled?

In this essay I will attempt to address the questions posed. Particular attention will be paid to CF testing itself. Pertinent aspects of CF and the prenatal testing for CF will be discussed.

It will be argued that given the current state of the science and the ethical implications at stake, it is irresponsible for the medical community and the federal government to continue offering prenatal CF testing. Serious thought to the eugenic practice and cultural implications of prenatal diagnosis needs to be considered before adding additional tests.

Clinical Aspects of Cystic Fibrosis

CF is a life-threatening autosomal recessive genetic disease affecting more than 25,000 Americans. About 800 new cases are diagnosed each year. The incidence of CF in Caucasians is 1 in 3500 live births (with a carrier rate of 1 in 30), and in non-white populations it is 1 in 12,163 (with a carrier rate of 1 in 56).

Approximately 1000 mutations of a particular gene on chromosome 7 have been discovered since 1989, all of which can cause the characteristic cellular chloride channel defect. This defect leads to tenacious mucus production in the lungs and pancreas and high sweat chloride levels. This defect causes the characteristic pancreatic insufficiency (leading to malnutrition) and chronic obstructive lung disease with recurrent lung infections. Severity of lung disease is the primary determinant in the quality and length

of life. Ninety percent of persons who have CF die from pulmonary complications. Several key organ systems are not affected by CF. Intelligence and cognitive function are typically normal. The musculoskeletal system is not directly affected.

CF has a highly variable course that is continually being affected by emerging therapies. Some patients have severe pulmonary and/or gastrointestinal disease presenting by the first year of life, whereas others have relatively mild disease not presenting until adolescence and young adulthood. The median survival of patients has been increasing during the past 4 decades. In 1976 it was 18 years, in 1995 it was 30.1 years and in 2004 it was 35.1 years.[6] It is important to recognize that survival of CF Foundation patients, which is the patient population that generates the data, reflect the therapeutic advances of the previous decades. Patients diagnosed through newborn screening programs are showing a relatively flat survival curve, leading to survival estimates exceeding 50 years.[7] A survey in 1995 reported that 35% of young adults with CF work full-time and 90% had completed high school.

CF Testing and Genotype-Phenotype Correlations

As mentioned, there have been over 1,000 mutations of the CF gene identified, and more will likely be discovered. There is one mutation, named Delta F508 that is responsible for 70% of the cases of CF in Caucasian populations. It is less frequently the mutation in non-white populations. The number of mutations that are being tested for is increasing rapidly concurrent with the progress in the HGP. Prenatal testing occurs in a one-step (both the woman and the man are tested simultaneously), or a two-step process (the woman is tested first. If she were a carrier, the man would be tested).

The most vexing issue regarding testing is the meaning of the test results. If both a man and woman are carriers, an amniocentesis or chorionic villus sampling is performed to test the unborn child. If the child is found to be homozygote for CF (i.e. inheriting both parents' mutations), he or she is classified as having CF. The child has a CF genotype, but there is a great deal of uncertainty as to the extent of disease the child would have if allowed to be born. What would be the phenotypic expression of the disease? The NIH's statement on this issue is important:

> The correlation of genotype with phenotype is substantial for pancreatic function; however, identification of the specific CFTR [CF gene] mutation has not been highly predictive of the severity and course of pulmonary disease, which is the major factor affecting patient quality of life and longevity. Furthermore, there is evidence to suggest a role for modifier genes and environmental factors that are as yet identified.
>
> Virtually all males with classic CF have congenital absence of the vas deferens (CBAVD) [the sperm ducts in the scrotum]. However, there is a population of otherwise healthy males with CBAVD who have a high frequency of CF mutations. It appears that more than half of these males have 1 or 2 specific mutations, which identifies these genotypes as the most common cause of CBAVD. Some women with these genotypes are healthy or develop chronic sinusitis or bronchitis as the extent of their morbidity. *It is unclear whether such mildly affected individuals can be reliably identified by their genotype.*

> *Thus it appears that knowledge of the genotype is as yet of limited value in making predictions about the anticipated course of disease in an individual, although research to identify genotypes associated with relatively mild presentation such as CBAVD may prove useful in informed decision making*.[8]

The inability to predict the extent of the disease is highly significant. What this means is that an unborn child who tests positive for CF may have minimal if any disease (bronchitis, sinusitis or be sterile if a male), or the child may ultimately have extensive life shortening pulmonary disease. It is possible to predict the extent of pancreatic insufficiency, but it is not possible to predict the extent of the disease that would have the greatest affect on the child's life.

Informed Consent

In a review of the current state of CF prenatal screening, Farrel et. al. summed up CF testing in this way:

> "CF is one of the most complex single-gene disorders with extraordinary genotypic and phenotypic variation coupled to an evolving, inexorably improving array of therapies. Communicating information about prognosis is a daunting challenge, especially for healthcare professionals with limited experience in managing patients with CF, as is the case with most obstetricians."[9]

Is it possible to honestly convey the described information in such a way that would allow for a woman or couple to make an informed decision? Even if the

information is accurately conveyed and understood, is it possible for a couple to make a meaningful decision given the uncertainties of prognosis?

The same authors noted that geneticists believe it would require a trained counselor an hour or more to convey the necessary information for an uninformed layperson to make an informed decision. It is unlikely that this is happening in busy obstetrical practices.

Given the complexities of the diagnosis in the prenatal period, the meaning of the diagnosis once it is made, and the likelihood that insufficient information is being conveyed, there is great potential for doing more harm than good. There is potential harm to the mother, when she is expected to make a decision that has significant psychological implications for her. There is obvious potential harm to the unborn child. Such genetic counseling is inadequate at best, and may be irresponsible.

Nondirective Genetic Counseling is a Myth

Closely related to the issue of informed consent is the question of whether such counseling can be value neutral. Can the person counseling simply present the options in a morally neutral manner, despite the decision having profound moral implications?

I would argue that nondirective genetic counseling is not possible for the following reasons. First by simply offering a test the clinician is morally sanctioning the test at some level. The practice of medicine is a moral enterprise, inherently anchored in the duties to do good and not to harm. When a physician offers a course of action, it is implied that he or she is acting in the patient's best interest.

If a woman at 28 weeks gestation presented with mechanical back pain from pregnancy, I would not offer induction of labor to relieve her pain. Such a

recommendation would not be in her or the unborn child's best interest, and therefore it is not morally sanctioned. When I offer back exercises and osteopathic manipulation I am intending to do good and not to harm, and it is therefore a morally permissible course of action.

Even if the woman wanted to be induced and felt it was her "right," this course of action would not be morally acceptable. It would be violating the universal moral principle of "first, do no harm" to the patients involved. So I would not offer such a course of action, nor would I agree to such a course if requested.

In the same way, if I offer CF testing to a couple, I am implying that I am acting in the best interests of the patients involved, intending to do good and to first do no harm. I am not neutral with regards to the test. If I thought the test would do more harm than good, I would not offer it. Any test I order is not simply a "personal matter" for the patient. When I offer CF testing, I have "personally" made a decision about the test's merits myself.

Second, the intent of the test is anything but morally neutral. The explicit intent of the test is to diagnose CF in order to give the patient the option to abort the child. The intent is not simply to provide the couple information before the child develops symptoms. Newborn screening for CF would suffice for this, and the process is being instituted in several states.

Implicit in the analyses – often explicitly stated – of widespread carrier screening is that such screening should lead to a reduction in live births. This is contrary to the NIH's stated goal of "helping people make informed decisions." To be sure, it would be imprudent for an already fiscally strained health care system to implement a screening

program that will cost millions of dollars simply to make "more informed reproducers (p. 761)." The NIH betrays their own goal when they include a cost benefit analysis in their own position statement. The economic "benefit" in the analysis is money saved by a reduction in live births. It is the NIH's unspoken intent that prenatal testing will result in a decreased incidence of CF.

Most significantly, physicians tend to overestimate disability and under estimate the quality of life someone has with a disability or illness. As Song states, "To some extent the training of doctors tends to encourage the attitude of regarding abortion for impairment as an easier option than coping with a disabled infant."[10] It has been clearly shown that the way the information is presented regarding genetic screening will affect whether the woman chooses to have the testing done or not.[11]

With such information in mind, it is not surprising that women often feel pressured to have prenatal genetic testing done. The response below from a British survey for persons with disabilities is a case in point:

> "I was pregnant last year and came under severe pressure from every medical professional I saw about my decision to have no tests. Even when I pointed out that they were talking to a disabled person about the possibility of eliminating her child if it was disabled, they could not see how offensive it was."[12]

As a physician, I have personally had patients tell me they were pressured by other physicians to have prenatal testing done, or more significantly to have an abortion. Even more frequently the tests have simply been ordered as the "routine standard of care" – "It's time to get your 16 week blood work Mrs. Smith."

A woman I provided prenatal care for had a child diagnosed with a severe heart anomaly by ultrasound at 20 weeks gestation. The anomaly is virtually always lethal. Both a perinatologist and a geneticist recommended to the couple that the woman have an abortion. Despite being deeply offended by the recommendation and informing the physicians that she would carry the child to term, the suggestion was given on repeated occasions. There are other well-documented cases of patient coercion for prenatal testing.[13]

Nondirective genetic counseling is a myth. To conclude that it is value neutral is to betray one's own biases already. I know personally it is impossible for me to be morally neutral in the exam room. When I counsel patients on morally charged issues, I inform patients up front of my biases. I then give them the various rationales for the test. Patients actually appreciate when the physician is honest in his or her dialogue. A person who claims to be "nondirective" but then provides subtly directed information to persuade the patient to have or not have a test is being less than honest.

Cystic Fibrosis Screening and the New Mask of Eugenics

Historian and philosopher George Santayana said, "Those who cannot remember the past are condemned to repeat it."[14] This admonishment is apropos to the current discussion.

In the early part of the 20th century in the U.S. and Europe the scientific community and the cultural elite embarked on an ambitious program of racial betterment.[15] The intent of the movement was to guard the future welfare of society by encouraging the "desirables" to reproduce, and to discourage the "undesirables" from doing so. Inspired by the writing of Charles Darwin's cousin, Francis Galton, the

United States enacted laws restricting the marriage of the "mentally deficient." Forced sterilization laws for the "feebleminded, insane, criminalistic, epileptic, inebriate, diseased, blind, deaf, deformed and dependent", followed these laws. The dependent included "orphans, ne'er-do-wells, tramps, homeless and paupers."

These laws swept the nation. Their constitutionality was upheld by Supreme Court Justice Oliver Wendell Holmes in 1927, when he infamously declared in Buck v. Bell, "three generations of imbeciles are enough."

Most Americans do not realize that the seeds of the euthanasia movement in Germany were sown on U.S. soil. The German government adopted model laws from Virginia in 1933 that provided the legal basis for the eventual forced sterilization of 350,000 Germans.

Ultimately there were 33 states in the U.S. at one time or another that had sterilization laws. The forced sterilization of the mentally ill and mentally retarded continued through the mid 1970's. Ultimately through the eugenics movement more than 60,000 Americans underwent forced sterilization.

The crux of any eugenics practice can be summed up with one word, "desirable." Any eugenics practice is meant to decrease the number of undesirable individuals and increase the number of desirable ones. This was the intent of the cultural elite and the scientific community in the first half of the 20th century.

Is this not the same intent of prenatal diagnosis and selective abortion? This process singles out the same classes of individuals that were singled out by our predecessors: the mentally retarded and the diseased. Scientists, physicians and others working in the field of genetics typically reject the idea that eugenics is being

practiced. Their codes of conduct disavow any such practice. They claim that no legislative or social coercion is occurring, so to describe such practice as eugenics is wrong.

Is such disavowal and distancing from our country's recent tainted past justifiable? Song asserts, the new eugenics is

> not taking place in mental institutions or immigration stations. It is not being promoted by Conferences for Race Betterment or fostered by worries about the future civilization…Yet it may still have the same upshot – of decreasing the number of 'undesirable' individuals and increasing the number of 'desirable' ones. The location for the new eugenics is rather the pre-natal screening suite, the genetic counselor's office, the general practitioner's surgery, the abortion clinic.[16]

He asserts that though there is the rhetoric of neutrality, this is not the impression most women get. The woman's relationship to the process of prenatal testing

> might best be described not so much as informed consent as acquiescence, in which the medical practitioner trades on an assumed agreement with the pregnant woman about what will be the best outcome (p. 53-4).

As discussed earlier, clear and comprehensive information regarding CF is not likely given to women. They're not told about the spectrum of disease in those with a genotypic diagnosis of CF. They are not told that many children and adults with CF lead meaningful lives. They are not told that emerging therapies are beginning to level out the survival curve.

There is clear evidence this type of biased "informed consent" has been practiced when screening for Down Syndrome.[17] Couples aren't told that the majority of children with Down Syndrome have only mild to moderate mental retardation. The vast majority of affected children are highly functional and readily integrated into society. Children and youths with disabilities often make positive contributions to their families, and the negative effects of a child with a disability have been overstated.[18] One needs only to attend a local Special Olympics to realize this side of disabilities.

Cystic Fibrosis screening and other prenatal tests are nothing short of practicing eugenics. It's not the eugenics of legislative coercion. It is eugenics with a new mask. The coercion is subtler, not pounding down the front door with forced sterilization. It enters through the back door of the clinician's office. Law does not enforce the elimination of the undesirables. They are eliminated by the imbalance of power in the exam room. A Supreme Court Judge is not necessary, only a physician in a white coat. The "sterilization" is done in the dark of the womb.

Didn't You have an Amnio?

If prenatal screening for CF becomes mainstreamed, it is inevitable persons with CF and their family members will be singled out for discrimination. Whenever a disease is targeted for removal through medical technique, it will become abnormal for the presence of the disease to be present in society. A relatively benign example of this is seen with immunizations. "Didn't your child get the Chicken Pox vaccination?" This is a refrain parents here now, if their child contracts the disease.

In the same way, the presence of CF will be considered abnormal in the population if a systematic prenatal diagnosis program is instituted. In Chicken Pox, it

is the presence of the *disease* that constitutes the missed opportunity. Such a presence is transient and leads to little long-term discrimination. In CF, it is the presence of the *person*. As long as the person endures, there will be subtle and not so subtle forms of discrimination against the parents and the person with the disease.

Parents of children with Down Syndrome are already being asked, "Didn't you have an amniocentesis? How did this happen?"[19] I had a colleague share with me recently that, though she is decidedly opposed to abortion, when she saw a child with Down Syndrome, her immediate thought was, "Didn't the mother have an amnio?" She instantly felt repelled by her own thought, but nevertheless the thought was there because of the accepted practice.

There has already been one case of clear prenatal discrimination of a mother with a child diagnosed with CF. Once it was discovered that the unborn child had CF, the mother was informed that the HMO would cover the cost of an abortion, but the child would not be covered under the insurance policy if carried to term.[20]

As the armamentarium of prenatal screening increases, such intolerance will only increase. The President's Council on Bioethics provides the following reflections on this trend:

> "Yet as the range of detectable disorders increases, as adult screening becomes ubiquitous and every pregnancy is tested, and as the economic costs of caring for the afflicted remains high, it may become difficult for parents to resist the pressure, both social and economic, of the "consensus" that children with sufficiently severe and detectable disabilities must not be born…furthermore, as our table of detectable genetic

> markers grows complete, there is the prospect of using genetic screening to weed out not only the most devastating genetic disorders but also heritable conditions that are bad but manageable, or even merely inconvenient. In practice, it is likely to prove very hard to draw a bright line between identifiable defects that might justify discarding an embryo or preventing a birth and those defects that parents might (or should) be able to find acceptable. It is not clear what resources our society will be able to draw upon to assist parents in making such important decisions."[21]

The Reproductive Board of Trade

Closely associated to the discrimination of persons with CF and their families, is the power that such quality control measures will have on the parent-child relationship. Screening for CF is only the beginning, and it is a paradigm for future screening tests. As the desire to achieve a disease free legacy grows, children will no longer be unconditionally welcomed members of the family regardless of the cards they had been dealt by life. They will be manufactured commodities fashioned after our choices.

Song astutely connects this propensity with our culture of consumerism. A consumer culture is a culture that "turns the world into goods to be consumed: that is, it turns things which were previously regarded as beyond the reach of the money economy into property and subjecting them to criteria of selection and quality control."[22]

As genetic medicine continues to become more exacting in the conditions it can identify, who will be acceptable commodities in the family and the community? Certainly a child with CF will not. Will children with dwarfism, dyslexia, a risk of asthma or type 1 diabetes be selected out? Are such children an acceptable commodity? What happens

when genetic medicine makes a mistake and a child with CF "slips through the cracks?" Will this child be welcomed with open arms? Will wrongful life suits become the norm?

Each of us is genetically flawed at fundamental levels. All of us carry genetic variants that predispose us to disease, upwards of a few dozen each.[23] If we were fortunate enough to escape the lottery of inheritable genetic disorders, and sneak past the genetic predisposition to common acquired pediatric disorders, we still have lurking in us the predisposition to premature cancer of various sorts, early onset cardiovascular disease, inflammatory diseases or a host of other conditions. To be able to assess for such risks is on the immediate horizon.[24] Conventional wisdom is dictating that such tests will also be used to increase the "reproductive choices" of couples. But are we increasing our freedoms by becoming the arbiter on who is fit to be born?

CF Screening and the Abolition of Man

CF screening, along with the already mainstreamed quadruple screen, is the prototype for the future of the new eugenics. These tests reflect the promised tools of greater control over the lottery of nature, techniques to rid our selves of the undesirable outcomes of reproductive chance. The great irony of increasing control over the nature of our species is the paradoxical loss of control each subsequent generation will experience. C.S. Lewis prophetically wrote about this threat over 70 years ago, long before the era of prenatal diagnosis.

> "The final stage is come when Man by eugenics, by pre-natal conditioning, and by an education and propaganda based on a perfect applied psychology, has obtained full control over himself. *Human* nature will be the last part of Nature to surrender to Man. The battle will be won. We

shall have taken the thread of life out of the hand of Clotho' and be henceforth free to make our species whatever we wish it to be. The battle will be won. But who precisely, will have won it?"[25]

Lewis concludes that ultimately, "Man's conquest has proved to be the abolition of Man." Once we have gained such control over ourselves, we will no longer be humans endowed with the dignity given to us. We will be the shrunken humans portrayed in Huxley's *Brave New World*, our freedoms stripped by fashioning ourselves after our own fancies in the decanting of humans in test tubes.

A Look Into the Future and a Call for a Moratorium

Imagine this scenario in the very near future:

You are a couple presenting to the doctor's office for your first visit to discuss the results on your prenatal testing. The white coated doctor steps into the examining room with his hand held device displaying your results. No congratulations are given because both he and you know that the pregnancy is tentative at this point.

He plainly states, "I have some good news and some not so good news. The conceptus does not have Cystic Fibrosis despite you being a carrier. But as discussed, we ordered the other standard tests to assess the health of the conceptus. Unfortunately it has an increased risk of a variety of conditions. It has a 55% chance of developing type 1 diabetes in childhood, a 65% chance of developing premature coronary artery disease, and a most unfortunate 80% chance of developing colon cancer before the age of 50.

"As you discussed with the genetics counselor, you can choose to carry this pregnancy to term. You must be aware that these risks are real though, and you will be required to sign a consent form, agreeing to continue with this pregnancy. If you

choose this course, you will assume the costs of all potential expenses from these conditions. The other alternative would be to terminate this pregnancy, and then return for a trial of IVF and PGD (pre-implantation genetic diagnosis)."

You are fully aware of this option, since the majority of your friends have already taken this less risky path. You had simply hoped to play the dice and have a healthy child naturally. After a bit of discussion you elect to go home with the medicine to induce the abortion, and to return in a month to begin the process of creating a healthier child.

If our medical community and culture at large continue in its current direction, this scenario will be hypothetical for only a brief period in time. The genetic tests to assess just such risks will be available in the near future. Once the tests are developed, it is doubtful that there will be any political will to prevent such tests to being applied in the setting of pregnancy. No line in the sand can be drawn between the testing of CF, Down Syndrome, or any other genetic or chromosomal disease. In the end, most diseases have a genetic basis.

What is the basis for making any such choices in the first place? At its most fundamental level, is the assumption that there is no inherent dignity to the human species. Such choices go far beyond the pale of wanting to decrease – or altogether eliminate – any potential physical disability or suffering in the world. Such choices must assume that the value of human life is ultimately tied to functional qualities such as independence, intelligence, health however defined, and whether another person is wanted or not. When any member of the species, whether in the womb, in the petri dish or in the hospital bed falls below some arbitrary level of value, the member is expendable.

Are such choices in our own best interests? We only need to look one another in the eye to realize they are not. To begin to make such choices is to say to each other, "you are not worthy to exist if you fall ill." We are all fundamentally flawed genetically. Who will be left if we select out our very selves?

We must resolutely decide to take another course. The medical community must halt in its application of genetic tests in the prenatal setting. The first step is to not allow CF testing to become a "standard of care" in the management of pregnancies. A moratorium on such testing needs to be made.

The focus of such testing should in other settings. For example a pre-dating genetic testing program for Ashkenazi Jews in New York City has resulted in a dramatic reduction in Tay-Sachs disease, a uniformly fatal condition in childhood. Similar testing is occurring in the same population for CF.[26] As emerging therapies definitively prove the benefit of early diagnosis, newborn screening for CF should become the standard.

But how far should we go? Will we begin to limit our freedoms in unanticipated ways as we apply more genetic tests in the general population? In cultural settings where there is an atypical mixing of severe lethal recessive traits, such interventions appear to make sense. But what other risks are we hoping to eliminate? Will we be able to tolerate any risks? Will we look like the cast in *Gattaca*, cold and stoic, never letting ourselves know the joy of spontaneous passionate love between a man and woman. Must we keep a cool distance from each other until we know that the other is "genetically safe?" I suspect we would be better off not knowing.

Life is a risk and we live in a broken, risky world. The application of technique, no matter how sophisticated will not eliminate the risks nor ultimately restore that

which is broken. To look to Technique in such a way is to search for an elusive hope, which ought not be sought from one another. Such radical hope will never come from our selves.

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