"Every Generation…"
A Jewish Approach to Questions of Genetic Research, Testing and Screening, and Gene Therapy

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The sun sets over rolling meadows as I drive by, through the far reaches of Rockville and towards our home in North Potomac, Maryland, casting shadows over the white fences and the wandering cattle. The farmland helps defy the definition of our area as "strictly" suburban. But we know, with a hint of sadness and a sense of inevitability, that the clock is ticking on the cows and the farm. The land is owned by an elderly woman, last of generations of family farmers, but has been pre-sold on the occasion of her death. Our future neighbors will be gleaming new office buildings, still more space in the sprawling complex that makes up the bio-tech boomlet so visible all around us. The farm will someday give way to additional administrative wings and research labs… of the Human Genome Project.

In the meantime, fights break out at School Board hearings all around the country over teaching science in light of passionate personal commitments to the surface and superficial readings of the first two chapters of the book of Genesis. Many people in this country seem to believe in a literal Adam and Eve, and oppose the idea of the evolution of the species.

And yet, and yet… There is another way, a spiritual approach which takes religious tradition *seriously,* but not *literally.* I have always believed that Adam and Eve were not the actual first, but the quintessential prototypes of all human beings, that the story, in fact, is a powerful tale of what happened not so much *before* our time, but *within* our lives. For this first couple was given one rule, and one restriction: do not eat of the fruit of the tree of knowledge. (The "fruit," by the way, was an "apple" only in Christian interpretation. In Judaism it was either a fig – after all, didn't they wrap themselves in fig leaves? – or an "etrog," a cousin of the lemon. Early Christian interpretation used an apple because that fruit had connotations of sexuality in the Roman world, and Christian interpretation has seen this story as being about sex. Jewish tradition does not interpret it in this way.) Do not reach out, to know what you have not known, to go where you have not gone before. Stay put, and stay safe; remain in the Garden.

But to reach out for new knowledge is what *makes us* who we are. The human story then, *begins* with the eating of the fruit. It is what takes Adam and Eve from naïve innocence into the world of adult human experience. More than that: this may be a story of divine disappointment that we could not stay "close" in our original created state, but it is also a story of human growth. For me, at least, this is not about a sin that taints all future generations, but the next step in the human path.

For we are going to reach out for new knowledge. We are going to reach for the stars, and split the atom. We are going to poke and prod into the stuff and substance of the world around us, to climb mountains because they are there. It is who we are. The spiritual, the religious, the moral question is not will we seek new knowledge, not "what if," but, in the face of what we find: "what now?"

Rabbi David Saperstein, head of the Religious Action Center of Reform Judaism, has forcefully remarked (and I paraphrase his observation here) that every generation has felt itself at the cutting edge of history. The only difference is that "because of our recent sweeping changes in technology, they were wrong, and we are right." In my own words: every generation has felt itself on the verge of a Brave New World, with unprecedented abilities and an "everyday" realities which would seem miraculous to those who lived in centuries past. But today, in a world of the split atom and the double helix, of space exploration and environmental degradation, of mutated crops and newly stubborn famine, of heart implants and heartless poverty which prevents access to even basic medical care to growing billions at the bottom rungs of the chain of human existence, today it is clear that we alone stand in a place where no one else has stood: able to shape or alter all life on this planet – or destroy it; able to tinker with the very fabric of human life – or dehumanize all our interactions with each other. They were wrong. And we are right: that the decisions we make today will affect our human future forever.

We are able to be saviors or monsters. The tragedy is that we are so torn as a society that different people will use each of these words to describe the very same act.

How clearly this is the case in what we face with the new frontiers of bioethics. Such questions have been in the headlines of late, from Terry Schiavo to *Million Dollar Baby.* But since the human experience of dealing with the unexpected and ambiguous, with love and loss, with aging and diminution of our abilities, of frustrating "grey" when we want "black and white", since this experience is universal, the more relevant question is why aren't these issues in the headlines *all* the time?

Of relevance, perhaps, to our discussion about genetic research and therapy, puzzling and problematic words of warning emerge from the Jewish tradition, in the midst of the over-hyped and under-read Ten Commandments. For there, in the midst of what Jewish tradition considers the Second Commandment, are the following words: "For I, the Eternal your God, am an impassioned God, visiting the iniquity of the ancestors onto the third and fourth generation of those that despise me, but performing lovingkindness onto the thousandth generation of those who love me and keep my commandments." This is what *Jewish* tradition considers the Second Commandment. (Catholics and Protestants actually count the "Ten" slightly differently: one more indication of the inappropriateness of governmental endorsement and display of a set of religious writings.)

How is this related to genetics? It is a reminder, if ever one was needed in this Postmodern world that emphasizes this truth again and again, that "we are who we were," that we are shaped in ways beyond conscious understanding by our parents and our past, that we inherit not only potential we did not earn, but also problems we do not deserve.

To begin to define a Jewish approach to this Brave New World of genetic testing and gene therapy we must distinguish between two modalities, two different ways of approaching Jewish texts. In our tradition there is both *halachah* and *aggadah,* "law" and "lore," distinct elements (unless said with a thick New York accent, in which case they almost blend together). The first is the realm of the Jewish legal tradition: what's a Jew to do? The second is the world of homiletics and legends, stories and tales from which underlying insights may often be teased out, but which were not originally meant to tell us what to do.

While the division is not as clear cut as this, as an oversimplification of the matter more traditionally observant Jews (Orthodox and some Conservative Jews) live in the world of Jewish law. For them, *halachah,* as interpreted by the interaction between ancient texts and modern practitioners, determines action. For more liberal Jews (Reform, Reconstructionist, and some Conservative Jews), *halachah* offers guidance, but *aggadah* may be a way of reading new situations into the tradition as well. The fact is that both "law" and "lore" are important sources of values, and often when faced with the delicate act of trying to figure out what an ancient tradition has to say about a very new situation, we will turn to both expressions of the Jewish spirit, and still not be sure of what "Judaism" has to say about any given topic.

The entire enterprise of using ancient sources to address modern ethical situations is fraught with peril: it is inevitable, if a tradition is to remain "relevant" to the modern world, yet it is problematic. One of the best treatments of this balancing act is found in an article from a decade ago by ethicist Louis Newman called "Woodchoppers and Respirators: The Problem of Interpretation in Contemporary Jewish Ethics." (1995)

Indeed, when approaching any topic of Jewish life it is useful to keep in mind the axiom that "where there are two Jews, there are three opinions." Judaism has no central hierarchical structure that determines doctrine, and even within similar streams or denominations of Judaism (Reform, Conservative, Reconstructionist and Orthodox), opinion on a subject is a matter of building a bridge between the past and the present, and thus depends on argument, persuasion, communal consensus, and continual openness to new insights.

There are often surprising outcomes of these discussions. To cite just two examples: the normally more "liberal" Reform movement scholar Mark Washofsky argues strongly for using great caution in the removal of a feeding tube, and the normally more restrictive Conservative movement's Elliot Dorf argued for more open conditions for allowing it. An Orthodox rabbi named Azriel Rosenfeld argues for the possibility, in the future, of allowing genetic manipulation of offspring even for non-therapeutic purposes, such as to enhance certain desirable characteristics (intelligence and appearance); Conservative Rabbi David Golinkin views such techniques as permissible only for what we would commonly understand as medical purposes.

And as implied above, disagreements exist even between those in the same denomination. Rabbi Elliot Dorf often writes from the so-called "liberal" end of the Conservative movement, and is challenged by others in his movement; Rabbi Mark Washofsky writes from the "traditional" end of Reform Judaism and encounters many more liberal voices amongst his colleagues.

All denominations of Judaism, however, are beginning to address questions relating to genetic testing and gene therapies with increasing frequency. A common thread to all branches of Judaism is the notion of *pikuach nefesh,* the "saving of a life." To save a life all the proscriptions of Jewish law may be set aside save three: you cannot commit murder, rape or idolatry even to save your own life. But there is general agreement that anything else can be done – *anything else* – if it will save a human life.

The temptation, then, is to end the discussion before it begins. The Talmud or Jewish law codes could even have directly addressed questions they never actually dreamed of, such as an amniocentesis or mapping the human genome, prohibited all of it, and those prohibitions could be set aside if the benefit of doing so would be to save human life.

It should surprise no one by now to realize that the question is more complicated than that. For what is *pikuach nefesh?* How broad a brush do we use? Or how specific a threat are we talking about?

Autopsies, for example, are generally prohibited by Jewish law, as a kind of desecration of the body, which is supposed to be buried – intact, untampered with, in its natural state, *as soon as possible* after a death has occurred. An autopsy required by the state may be allowed by traditional authorities, under the principle of *dina d'malkhuta dina* ("the law of the land is the law," that is, the laws of the land we live in in most cases have the power of Jewish law as well), but even then the autopsy must be done *quickly!* But what about an autopsy that might be medically beneficial to others? A liberal reading of *pikuach nefesh* would allow the autopsy, for the chance that the information gleaned might someday save someone else. A more strict interpretation (followed, in this case, by most traditional authorities) would argue that if a specific autopsy of a particular person might be of *direct benefit* in saving the life of a *specific, known* other individual, then, and only then, might an autopsy be allowed.

So the principle of saving life is valuable to keep in mind, as a reason why some genetic testing might be permitted in Jewish tradition. But it is not a *carte blanche.* It cannot serve as a blanket protection to cover all cases.

What, then, does Jewish tradition have to say about key questions in the ever-changing, cutting edge world of genetic research, testing and screening, and gene therapy? I will examine several partially overlapping areas under consideration – the amniocentesis procedure, Tay-Sachs screening of adults, Huntington's disease, and breast cancer screening. This will begin to paint a general picture of how Jewish tradition treats these subjects, and how Jewish patients might turn to, base their decisions on – or perhaps rebel against – this background. It is an important part of Jewish tradition to give credit to one's sources and one's teachers: in the remarks that follow I base my comments extensively on the writings of Mark Washofsky (Reform), Elliot Dorff (Conservative) and Fred Rosner (Orthodox), whose respective works on Jewish bioethics have become important references in this field.

Pre-natal testing to obtain genetic information about a fetus in utero is a rapidly evolving field. Even in the time since my youngest child was born in 2001, new options are available to obtain increasing amounts of information in decreasingly obtrusive ways. Observations that once required an amniocentesis can be made earlier now simply through enhanced sonogram technology and other tests. In this way the risk-benefit analysis and the age-recommendation that I am familiar with (maternal age of 35 being the "tipping point" between the rate of risk of miscarriage and the rate of benefit of detecting genetic abnormalities) will undoubtedly change in the relatively near future. What will also shift as the technology changes, then, is the ethical consideration of whose "interests" are being served, and of who is the "patient" in question.

Having said that, however, I believe that one of the major issues behind pre-natal testing remains the same no matter what method of testing is used to employ the information. It is the underlying question of what to do with the information. It is the debate about abortion.

As it plays out within Jewish circles, there is actually one aspect of this debate about which there is universal agreement. In the case of a threat to the life of the mother, abortion is *mandated.* It is not seen as a choice. It is not seen as an option. It is an *obligation.* All branches of Judaism are in agreement about this point (which rarely happens about anything.)

The question, though, is *why?* How we answer this question will determine whether abortion is allowed by Jewish tradition in other situations. And here, as expected, there is heated disagreement. As a brief, oversimplified rendition of this argument: *If* abortion is allowed to save the mother because the fetus is considered a "pursuer," and abortion is allowed as a kind of "self-defense," then the fetus does seem to have the status of a person, and would not be allowed for other reasons. *If,* on the other hand, the fetus is considered "merely water" for the first period of development, or "like a limb" of the mother, then abortion may be allowed for other compelling reasons, although not, in the second case, for just *any* reason (since self-mutilation is not allowed; you cannot cut off your arm just because you want to).

In general, many Orthodox rabbis today believe that abortion should be limited to the extreme situation of danger to the life of the mother, and the non-Orthodox branches of Judaism (Reform, Conservative, Reconstructionist, along with *some* Orthodox authorities) allow for abortion in cases where the pregnancy poses a danger to the health of the mother as well – including in this consideration emotional and mental health.

These are not abstract issues. And the question of the cultural and religious environment in which a patient lives is directly relevant to medical decisions. My wife and I lived in Erie, Pennsylvania through our first two miscarriages, all of our first successful pregnancy and much of our second successful one. My wife was just 35 at the time of the birth of our first child, and we explored with our physicians and, having had two previous miscarriages, struggled with the question of whether to have an "amnio." Only a few places in Erie performed the procedure, and when we mentioned to people that my wife worked with that we were thinking about getting it, they responded: "Why? What would you do with the information, anyway?" In a heavily anti-abortion environment, getting this information was seen as… almost superfluous.

But the fact is that there are certain outcomes which *would* have led us to terminate a pregnancy. And I can't say for sure how we would have reacted if the results had been problematic. Certainly in anticipation of some conditions we would have cried, and prepared. But in others… Many -- perhaps most -- of those dealing with this question vis a vis Jewish tradition would not require a couple to bring a child to term who would die a horrible and painful death in the days soon after being born.

On the question of abortion, then, Judaism is not "pro-choice" *per se,* if by "pro-choice one means "do whatever you want." But because the decision is seen to rest on a case-by-case basis, and depending on the particular medical circumstances *and* upon the impact it would have on the *individual* family involved, Judaism can, I believe, fairly be described as being *politically* "pro-choice." This matter should be in the hands of the woman, the family, the physician… and, for Jewish families, in consultation with Jewish religious tradition.

All of this is background to saying that pre-natal genetic screening is generally allowed in Jewish tradition, without huge reservations in the non-Orthodox branches of Judaism, and with some hesitation by many Orthodox authorities. ("If the cure to these conditions becomes available in the future," an Orthodox argument might go, "then such screening would be rendered unnecessary" On the other hand, of course, if it were possible to correct such conditions *before birth,* the argument might tip the other way.)

What about, then, advance screening of adults for genetic conditions which they might pass on to their offspring? The condition that comes immediately to mind when discussing a Jewish approach to genetics is that of Tay-Sachs disease. According to the National Institute of Health, "Tay-Sachs is an inherited disorder caused by the absence of a vital enzyme, resulting in the destruction of the nervous system. It is always fatal; to date there is no cure."

A more detailed medical presentation of the condition describes Tay-Sachs as a fatal genetic lipid storage disorder in which harmful quantities of a fatty substance called *ganglioside* G_{M2} build up in tissues and nerve cells in the brain. The condition is caused by insufficient activity of an enzyme called *beta-hexosaminidase A* that catalyzes the biodegradation of acidic fatty materials known as *gangliosides*. Gangliosides are made and biodegraded rapidly in early life as the brain develops. Infants with Tay-Sachs disease appear to develop normally for the first few months of life. Then, as nerve cells become distended with fatty material, a relentless deterioration of mental and physical abilities occurs. The child becomes blind, deaf, and unable to swallow. Muscles begin to atrophy and paralysis sets in. Other neurological symptoms include dementia, seizures, and an increased startle reflex to noise. A much rarer form of the disorder occurs in patients in their twenties and early thirties and is characterized by an unsteady gait and progressive neurological deterioration. Persons with Tay-Sachs also have "cherry-red" spots in their eyes. (NIH)

The incidence of Tay-Sachs is particularly high among people of Eastern European Jewish descent. While there are both Jewish and non-Jewish carriers of the recessive TSD gene, 85% of its victims are Jews.

Approximately one in 25 Jews is a TSD carrier. In the non-Jewish community the rate is one in 250.

A carrier couple (that is, a couple in which *both* parents are carriers) is "at risk" and has a one in four chance with each pregnancy of producing a Tay-Sachs baby; the chance for an unaffected child is three in four.

There are tests available which can determine whether adults are "carriers" of Tay-Sachs. *Genetic counseling in general* (as well as a specific recommendation that adults be screened for Tay-Sachs – preferably before the wedding, but definitely before a pregnancy) is now a routine part of the pre-marital counseling offered by many rabbis. My own pre-wedding packet contains detailed information about Tay-Sachs (and can be seen at www.templeshalom.net/documents/marriage-packet.pdf).

Death from Tay-Sachs is painful, prolonged, horrible and, at this time, inevitable. What possible objection could there be to doing everything in our power, from advance screening to pre-natal testing, to eradicate the disease?

The objection, raised in certain circles of the Orthodox world, relates to the question of the impact of the information on the individuals found to be carriers, or on couples who are already engaged. There is a fear of a stigma attached to a person found to be a carrier, so that the person would be seen as "damaged goods," and thus less likely to find a mate. There are concerns about the stress that the information will cause to the carrier as well, and great fear about the chance that an already engaged couple would break their engagement upon learning that they are both carriers. The context to these concerns is the strongly pro-natal position of Jewish tradition: marriage is viewed as the ideal adult state, and having children is considered a *commandment.* (Interestingly, in an odd twist that is an early nod to issues relating to women's role and rights, the commandment to bring children into the world falls on *men*, rather than women – a recognition that child-bearing can be dangerous and for some women life-threatening, and one cannot be commanded to do something that might endanger one's life. An early illustration of *sensitivity* to women, however, was subsequently subverted by the implication of this realization – for if a couple cannot have children, in some ultra-Orthodox circles the man is expected, indeed perhaps even pressured, to divorce his wife, and try again with another woman. No matter the first couple's feelings for one another.) *Not having children* because of a statistical possibility that they might have Tay-Sachs disease is not, therefore, generally seen as an option in the Orthodox world.

The concerns expressed above, however, can be dealt with. An organization called the Association of Orthodox Jewish Scientists issued a paper, in 1973, calling for "voluntary screening of young adults of an age in which marriage has become a serious consideration but before definite marital commitments have been made." Earlier screening would lead to unnecessary additional stress; screening of an engaged couple might lead to the dissolution of the relationship.

The common practice in non-Orthodox Jewish circles, however, is to recommend such screening to an engaged couple and, as mentioned above, it is usually raised as part of rabbinic pre-marital counseling.

Most (but not all) Orthodox authorities would prohibit an abortion of a fetus found to have Tay-Sachs disease (and some ban amniocentesis altogether); most – perhaps the vast majority – of non-Orthodox authorities would allow an abortion is this case.

Rabbi Elliot Dorf, in his recent and very readable work *Matters of Life and Death: A Jewish Approach to Modern Medical Ethics,* treats two other areas of genetic testing of adults: Huntington's disease, and breast cancer screening. As described by the National Institute of Health, Huntington's disease "results from genetically programmed degeneration of brain cells, called neurons, in certain areas of the brain. This degeneration causes uncontrolled movements, loss of intellectual faculties, and emotional disturbance." It is passed from parent to child through a mutation in the normal gene. The gene is dominant, which means that each child of a parent with Huntington's disease has a 50-50 chance of inheriting the gene. It leads to dementia, disability and death.

A pre-symptomatic test is now available for those individuals at risk for carrying the gene. The moral and spiritual question basically is this: do you *really* want a crystal ball? Do you want to know? Since the age of onset of the disease varies greatly, is it better to know what is coming and prepare, or live your life as long as you can? And in this age of the internet and NSA spying – who knows who will get the information? Rabbi Dorff raises the immediate implications: How will this affect insurance? Employment? Choices about whether to marry, to have children? And: crucially – does one who knows that one faces a deadly disease later in life have an obligation to disclose this information? To whom, and under what circumstances?

The gene for Huntington's disease, once detected, is a direct and dire indication that one will contract the disease. What about a case of genetic probability, rather than certainty?

I sat with a young couple in my study just as I was getting ready to finish writing this chapter. They are getting married in a few months, and we are going through my usual procedures and questions, reviewing the details of the processional, the role of photographers, and the intricacies of whatever personal issues of communication or couples counseling they may want or desire before the wedding. We reach and quickly move through the discussion of Tay Sachs. And then the bride-to-be asks me a pointed question. There is a strong history of breast cancer in her family. There are tests available now, to detect a gene mutation (BRCAI) that is a factor in many cases of breast and ovarian cancer. Much publicity has been given recently to the finding that Ashkenazic Jewish women have an elevated risk, in comparison to the general population, of carrying this mutation. She leans forward on the couch. Should she be tested?

And in one moment all the issues we have been discussing here come to a head. With two people in front of me, I feel the awesome weight of it all – the blessing and the curse of new knowledge, the opportunities (early action?) and risks (insurance companies?), the delicate dance of what the woman – and her husband-to-be – would do with the information, the inherent uncertainty of the whole business, at least at this stage, as the presence of the mutation alone is not perfectly predictive of what will come.

With the weight of the issues comes the irony of the question coming to me. Every practitioner should know the limit of his or her craft. The irony of my writing this article, in this case, is clear to me: my wife's sister is a nurse-midwife earning a PhD in Health Care; *her* husband is a philosophy professor and one of the leading ethicists in the country. Either of them, I felt, would be more equipped to sit in my chair at that moment, or to address so many of the issues here.

I suspect I am not alone in a sense of momentary isolation when facing questions of bioethics. These issues arise in similar settings, but with the unique stories and individual circumstances that come out of the human experience.

And so we remember that healing – whether the physical kind practiced by nurses and physicians, or the spiritual and emotional kind practiced by caregivers and counselors and clergy, is an art, as much as it is a science.

What do we know about our bodies? What are the mysteries science has yet to solve, the secrets yet to spill?

Soon the whole of the genome will be laid out before us. And reaching out for new knowledge, for more information, is what we do as human beings. But I reminded of Jeff Goldblum's character in *Jurassic Park*, who noted that we have spent so much time asking if we could do a thing that we have forgotten to ask whether it should be done.

Or more to the point here: we have spent so much time asking about information that we do not always dwell on application. We come back to the line between "what if" and "what now."

Our bodies and our minds and life itself are a gift from the One who creates and shapes the world. All I know for sure is that we will – and we should – keep on reaching out. We should move forward into this new world, using our minds to understand our bodies. But may we carry on in a spirit of awe, and reverence, and love, with some humility left in the face of the miracle of life, for some room still for amazement at the fact… that we are here at all.

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