Barely-Charted Territory: Some Ethical Considerations in Genetic Testing for Jewish Prospective Parents

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It's a wonder there aren't more Luddites around these days. Those of us living in economically developed countries seem to have acquiesced to a lifestyle characterized by rapid technological change that usually outpaces our ability to think clearly and innovatively about what we must do to keep ourselves feeling human – and acting humanely. One prominent example of such lop-sided change can be seen in the shift in medical research and practice from the curing of illness and alleviation of pain to the prevention of disease. (Indeed, prevention now extends beyond disease to certain conditions that are popularly perceived as pathological or defective; Down's syndrome, which will be noted later in the paper, comes to mind here.)

In contrast to the curing of illness --with its heavy reliance on the skills and instincts of human practitioners-- stands the kind of prevention now often accomplished through modalities introduced at the molecular level, a realm that in its minuteness is so very far removed from the influence of human interaction. For example, preclusion of certain hereditary disorders can be accomplished at this time by identifying abnormalities whose existence is only observed *within* the nucleus of a cell *within* one of its 46 molecules –chromosomes-- *within* a minuscule segment, a gene, found on a particular chromosome. When a sample of DNA-- the spiraling strands of chemical data that, gene by gene, make up the fabric of our inherited selves-- is taken from a prospective parent, it can be examined for the presence of an allele (a mutant form of a gene) that is recessive, i.e., not expressed as disease unless paired with its counterpart. When, however, two recessive alleles become paired during the formation of a zygote (the first manifestation of the joining of sperm and egg into an embryo), the disease is said to be ex-pressed. Since with each pregnancy there is a one in four chance that two recessive alleles will 'meet' to begin the process that ultimately leads to such expression, partners carrying

these defective genes can now be advised not to reproduce or to reproduce with the help of technologies that select for healthy embryos. * Indeed avoidance of physical defects itself no longer seems to be the ultimate medical destination; enhancement of what is good enough looms as the next frontier.

Prevention based on a sub-cellular scale, however, is still in its infancy as both science and art. And because it is a relatively new, rapidly advancing area of intellectual inquiry, its moral terrain has yet to be fully explored, let alone definitively mapped. Although this latter process will almost certainly not keep up with technological discovery, it must nevertheless be encouraged if we are to avoid one of the significant dangers of modernity expressed in Ralph Waldo Emerson's pithy remark, "Things are in the saddle, and they are riding us."

In the context of current medical pursuits, what kinds of 'things' – if not held in check with corresponding ethical quests –could threaten our humanity, our acting as if people and their well-being genuinely matter? Genetic testing comes easily to mind as one example, although the term stands for a wide variety of procedures. A sense of our collective potential to overstep human bounds and thus cause further deterioration in human interaction seems to pervade both popular and more scholarly treatments of the subject. In the decade-old film *Twilight of the Golds*, for instance, the pregnant sister of a mistreated gay man discovers through prenatal testing that the child she is carrying has inherited the 'homosexual gene'. Her husband, a doctor, voices the entire family's uneasiness about possessing too much in the way of factual knowledge and too little in the way of an ethical context in which to make decisions when he blurts out,
"Just because we can do [these tests] doesn't mean we should have."

> Approximately 50 years ago the Salk vaccine practically wiped out polio wherever widespread inoculation took place. Prevention of this communicable disease, by means of a physical, protective intervention, led to its near-eradication. Today, in the case of several inherited diseases, prevention is now one step removed from such pre-emptive intervention. Due to the predictive nature of genetic testing, some potential disorders can be dismissed before they can possibly appear. Risa Davis, coordinator of the Genetic Education and Screening Project of Jewish Family Services of Central Maryland reports, for example, that "Tay-Sachs [for which there is no cure] has been virtually eradicated through carrier screening."

In addition to the capacity of genetic testing to reveal seemingly more about individual futures than we can now handle on a human scale, both emotionally and rationally, there exists the idea that the information gleaned is

> …fundamentally different from medical information in both its psychosocial impact and potential for abuse of privacy and confidentiality. …A 2001 Harris Poll…found that the public's primary concern about genomic research is [its] potential misuse…by insurers, employers and government. [Therefore it is] unique and deserving of special legal protections. This belief –commonly referred to as genetic exceptionalism—is founded on several characteristics that many believe to separate [it] from other health data: [it is] predictive…it can identify an increased likelihood of disease in otherwise healthy individuals; permanent …remains largely stable from birth throughout life; identifiable …each person's genetic code pervades nearly all cells of the body and can be used to identify individuals with precision; familial …reveals information about the genetic composition of family members; prejudicial…a genetic predisposition may…stigmatize an individual. [1]

Questions, then, about the rightness and wrongness of the choices that grow out of these new kinds of considerations expose a virtual *terra incognita* devoid of familiar features. The identification of a genetic predisposition for a particular disease, for example, is not at all the same as a traditional diagnosis of an extant condition; the discarding of a defective eight-celled embryo which has been developing in a lab rather than in a woman's womb is not at all the same as a conventional abortion.

This paper will limit itself to some ethical ramifications for the Jewish community of those tests involving (1) potential parents, (2) viable but not-yet-implanted zygotes

[eggs successfully fertilized with sperm in a petri dish (*in vitro*) that have not yet been placed inside a woman's fallopian tube or womb for gestation], and (3) fetuses developing *in utero*. It must be noted, however, that many genetic tests unrelated to reproductive issues have been developed as well. Known as *predictive gene testing*, this sub-category seeks to identify, while still pre-symptomatic, those who are nevertheless at risk for particular inherited disorders, including cancers such as retinoblastoma [a rare childhood eye cancer], Wilm's tumor [a kidney cancer with onset usually before age 5], and the better known BRCA 1 gene mutation, which predisposes a woman to hereditary breast and ovarian cancers. Other predictive genetic tests are close to being ready for widespread use, including analyses that identify the mutated genes causing ALS ('Lou Gehrig's disease'), Huntington's disease, some forms of Alzheimer's, and 'catastrophically high' cholesterol. [2]

Further, in limiting its scope to genetic screening of Jewish potential parents and genetic testing of zygotes and fetuses –potential and developing offspring-- in order to prevent fatalities and severe abnormalities in Jewish children, this paper proposes that genetic identification *qua* Jewish identification must not be dismissed summarily by today's Jewish leaders who are called upon to share their understanding of what constitutes Jewishness. Despite the distasteful, even ominous, inferences that might be drawn from an awareness of 'biological Jewishness' as a foundation on which to rebuild the empty chauvinism of Jewish genetic superiority (and in the hands of malicious others, a 'race-based' conception of the Jewish people), it is imperative that rabbis and other influential Jewish spokespeople encourage individuals born of Jewish parents who are

themselves contemplating parenthood to treat their hereditary legacy as scientific reality and not merely historical accident.

Progressive Jewish thinkers of the 20th century, notably Mordecai Kaplan, did much to release Judaism from its ethnically-grounded self-definitions, thereby making its cultural and spiritual riches available to many not born of Jewish parents ('Jews by choice,' as they are now called) while at the same time offering natural-born Jews the opportunity to take on, more freely and willingly because appropriated more self-consciously, the joys and responsibilities of Jewish life. Yet successful Jewish genetic testing can only take place where the target population is sufficiently self-identified as Jewish in a way that is, strictly speaking, unrelated to being culturally or religiously Jewish. In a sense, this target population of adolescents and young adults (roughly speaking, 15- to 35-year-olds) must be encouraged by Jewish leaders to hark back to an understanding of Judaism that predates their grandparents' era, but only insofar as testing for fatal and severe forms of genetically transmitted disease is concerned. Although this notion of Jewish ethnicity, of being a member-of-the-tribe through bodily inheritance, may go against the grain of Jews who are committed to inclusiveness, or at least, to a widening of traditional boundaries of Jewish identification, it is nevertheless, this writer maintains, an understanding that is crucial to the well-being of particular Jewish families and to the health of the general Jewish community (which is often called upon to share the burdens of incurable and terminal childhood disease).

Fortunately, as cited above in the testimony of Maryland's Jewish genetic testing program director, the devastating and consistently fatal disease of early childhood known as Tay-Sachs has been all but eliminated among Ashkenazi Jews [those of eastern

European descent] thanks to 'carrier screening' for potential parents. Tay-Sachs as well as several other deadly inherited diseases common to this particular ethnic group – Niemann-Pick Type A, Canavan Disease, Cystic Fibrosis, and Familial Dysautonomia—are understood to have arisen in this population due to a 'founder effect' whereby a single ancestor passes on a genetic error, known as a mutation, to all of his or her descendants.[3] These diseases, however, afflict an individual only when she or he inherits *two* mutations, one from each parent. The parents, on the other hand, each possessing only *one* mutation, are merely 'carriers' of the disease to the next generation; they can never be afflicted themselves. In each pregnancy resulting from the union of two carriers, there is a 25% chance that the child will have the disease and a 75% chance that the child will be unaffected or will be only a carrier him/herself.[4]

> A brief description of a thriving carrier screening program in Baltimore, the Jewish Family Services Genetic Education and Screening Project, may serve to illustrate how questions of right and wrong and thus all shades of obligation from 'must' to 'ought' are deferred by design, leaving its own efforts as ethically unproblematic as possible. Since the program was created to serve all Jews with hereditary patterns of the Eastern European variety no matter what their religious affiliation or lack thereof, it limits its educational component to what can and cannot be done for carriers, not what should or should not be done by them.
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> To begin with, no pregnant women are accepted for screening since an expectant mother and her male partner might discover that they are both carriers and would then most likely want the fetus tested to see if it bears the disease itself. (This in turn could lead parents to the decision to abort, never an easy matter in Jewish tradition, as will be discussed later.) Further, phlebotomists who draw the blood samples receive only number codes to identify each participant, which are in turn passed on to the processing lab. Results are made available to no one other than the person tested; in fact, although a genetic counselor makes three attempts to reach each tested individual after the results have been mailed, he or she is not privy to the outcome of the tests before calling. Anonymity is preserved throughout the process. The designers of the program seem to have understood the intertwining of two Jewish mandates here: the guarding of one's tongue [*sh'mirat ha'lashon*] and the importance of providing each Jew an opportunity to earn a livelihood [*parnasa*]. Public access to the data might not only stigmatize an individual but also jeopardize his or her financial security if the individual were deprived of employment, housing, or insurance based on the potential need to spend much time, energy, and money in meeting the needs of a seriously ill child.

Thus within the context of the program itself the question of abortion and the dilemma of disclosure are both avoided. Interestingly enough, the disadvantages of abrogating confidentiality have also shaped civil law in many states. Writing in 2001, the head of the genetics policy taskforce of the National Conference of State Legislatures reported, "Laws in thirty-three states ban the use of genetic information in underwriting health insurance in both individual and group markets. …three states forbid discrimination unless actuarially justified [and] five address use of genetic information only in the group market". [5])

Carrier screening, however, like any other form of genetic testing, can never be a totally benign activity for testers or those tested. Even a negative result can be misleading: since testing evaluates only the more common mutations of a particular gene, an uncommon one may pass unnoticed, giving the tested individual a false sense of security – and the tester an eventual lawsuit. (The cystic fibrosis gene, for example, can appear in over 300 mutations.[6]) Research biologist Judith Wahrman describes two cases of Tay-Sachs babies born during the 1990's whose parents were confirmed not to be carriers.[7] And even if one lives in one of the thirty-three states with non-disclosure legislation, disclosure to a potential spouse or employer can be a complicated matter. In the case of Jewish genetic diseases, it forces all relevant parties to consider ethnicity as biological actuality rather than social construct and can even expose an ethnic identification that an individual's family may have been trying to hide. It is not so difficult to picture a purportedly non-Jewish spouse discovering his or her suspected Ashkenazi roots after agreeing to submit to this particular panel of genetic tests. (Or a variation on that theme: I learned from a friend that the TV series *Law and Order* based a recent episode on a Jewish woman who did not see the need for carrier screening for herself because she was married to a non-Jew. This grim story of the murder of a Tay-Sachs infant turned, however, on the fact that the woman had had a 'one-night stand' with a fellow Jew, which in turn led to a birth that she had originally intended to portray as one arising from her marriage. Choosing not to be tested oneself on the assumption that one's partners are immune from being carriers could conceivably turn out to be tragic in real life as well.)

Other carrier screening programs can be problematic because of the information they choose *not* to share. The *Dor Yeshorim* model is used in both the United States and Israel in Orthodox communities where arranged marriages prevail. Teen-aged boys and girls are screened with the same kinds of safeguards of anonymity as provided in the aforementioned program, but neither they nor their families ever learn the results --only the *shadchen* [matchmaker] is given that information so that she knows whom to avoid pairing. Occasionally, families will contact *Dor Yeshorim* , but they will find out only that an intended match is not suitable; they will not be told if their own child or they themselves are carriers. [8] Although this is done for an honorable reason, namely, to avoid stigmatizing a carrier or his/her family, the dangers of non-disclosure to the tested individual become apparent as soon as the strictures of this locally bound and highly traditional arrangement loosen or simply fray. Faulty record keeping can join two carriers without their knowledge. A young person, unaware of his or her genetic status, may leave a particular community and remain unmotivated in adulthood to retake a test performed during his or her adolescence. A community may experience information leaks that do isolate certain families. No matter what the cause, if two carriers who maintain their identification with traditional Orthodoxy are inadvertently joined in marriage, they are "obliged to procreate, even if there

is a serious genetic defect," maintains Rabbi David Bleich, who "opposes abortion of a physically malformed or mentally deficient fetus." [9]
The problems of a carrier who knowingly mates with another carrier can be increased or diminished --depending on one's point of view and one's cash on hand-- when in vitro fertilization (IVF) is used to forestall a pregnancy before it officially begins with implantation of the embryo into the uterine wall. This as yet unperfected process is available to some who face the possibility of having a child affected with Tay-Sachs, Niemann-Pick Type A, Canavan, Cystic Fibrosis, or the non-fatal but often extremely debilitating disease, Gaucher Type 1. Known as pre-implantation genetic diagnosis, or PGD, it involves genetic testing of individual zygotes, eight-celled embryos that appear as the first discrete stage of growth after a sperm penetrates an egg, that have been allowed to develop *in vitro*. In short, zygotes are tested for the same kinds of genetic mutations as potential parents who may be genetically predisposed to being carriers. If an abnormality is found, that embryo is 'discarded'; only a sound embryo is transplanted into the wall of the uterus. Miryam Wahrman observes in *Brave New Judaism,* a compendium of cutting-edge reproductive technologies and the halakhic concerns which they raise, that use of PGD to "weed out defective embryos is sanctioned by some rabbinic authorities, partially because the early embryo is considered *maya be'alma* (mere water)." [10] She amplifies this with the observation of Richard Grazi, author of *Be Fruitful and Multiply*:
This permissive attitude toward screening and implicitly, the discarding of the affected untransplanted embryos rests to a great extent on the lack of standing the embryo has in halakha. However, it is the psychological state of the parents which is invoked rather than any negative quality of life that the child might suffer.[11]

Parents who are both carriers of one of the diseases listed above are directly exhorted in a pamphlet published by FD Hope, an organization for families burdened by Familial Dysautonomia. It announces: "Couples who each carry the mutation are able to safely bear unaffected children with the development of pre-implantation screening…." But what of parents who cannot raise the $10,000 or more needed to perform all the steps of IVF to which are added the cost of microdissection and then DNA analysis? At the moment, at least, it must be regarded as a rather tidy technological alternative to the problem of abortion that nevertheless fails to address the issue of prohibitive cost, a very human problem with enormous ethical import. In addition, one could ask about the nature of what is getting 'weeded out' and thrown away: does it partake of life at all? How abnormal must something be in order to be considered defective? Given that genetic testing is predictive and therefore deals in "probabilities, not certainties", [12] to what extent can it successfully replace the actual diagnosis of a disease in progress?
A third form of genetic testing, the one that does indeed come closest to traditional diagnosis, involves sampling of actual fetal material, either through amniocentesis or corionic villus sampling (CVS), both of which can now be performed during the first trimester of pregnancy. While abortion of fetuses afflicted with any of the fatal childhood diseases is permitted in the liberal Jewish community [13] --such abortions are termed 'therapeutic' -- there are other genetic abnormalities such as Down's syndrome, and even to some extent, Cystic Fibrosis (although listed as a fatal childhood disease by the carrier screening program mentioned earlier) which considerably blur the criteria for abortion. Affected children can live into adulthood, often having

> rewarding, productive lives and bringing a sense of reward to those who care for them. Should their mothers abort?
> The Jewish tradition treats the anguish of a mother, her mental state at the thought of raising children with greater-than-normal demands on her physical stamina, her finances, her relationship to her other children and spouse, with utmost seriousness. How does one sort out true anguish from the perhaps transitory fear of not being up to the task? How long must a mother's anguished mental state last in order to be considered defining? The aforementioned diseases are the kinds of other-than-normal states that raise some of the most vexing ethical problems surrounding reproductive issues. Not only do these concern the shifting nature of definitions of pathology due to its highly cultural component, but they call to mind the human urge toward perfection and the simultaneous fear of playing God -- in this case, through sending a potential person into non-existence by virtue of information now available to us, on the molecular level, about its developing body.

Although carrier screening and other forms of genetic testing take us into largely uncharted ethical territory, several core Jewish values can offer illumination for this problematic terrain. Young people of Ashkenazic Jewish ancestry (and Sephardic ancestry as well, thanks to another panel of genetic tests for diseases specific to that ethnic sub-group [14]) can have a sense of moral guidance if they choose to lead lives shaped at least to some extent by a Jewish understanding of the world. These values grow out of *halakha* [the legacy of "commandments contained in the Torah, rabbinic legislation, and the practices that through usage have been sanctified in Jewish life" [15] which give numerous opportunities to commit acts regarded as holy in the Jewish tradition].

First and foremost, all Jews considering parenthood (even if they are not themselves aware of ties to Ashkenazic ethnicity) should be tested to see if they are carriers for the five autosomal-recessive fatal diseases listed above, bearing in mind that no test can be a completely infallible predictor of the condition of one's future offspring. Jews who take their tradition seriously subscribe not to the idea of exclusive personal ownership of one's body but rather to the idea that "God owns everything in the world

including the bodies of every human being" and that thus we are mandated to "take proper care of our health and avoid danger and injury." In fact, "laws regarding [the] endangering [of] one's life are more stringent than those regarding ritual prohibitions." [16] Not to test is to run the risk of potentially causing oneself danger and injury in the form of mental anguish associated with giving birth to or fathering a child who will suffer greatly and die young. Those young people who are not of known Jewish ethnicity (Jews by choice and adoptees from other backgrounds are two such populations) may also be tested, at a minimum, for the sake of solidarity with their community but more importantly because at least one of these deadly diseases, Tay-Sachs, has surfaced in other ethnic groups as well. (Those Jews who have been tested or who feel compelled to be tested, but end up resenting their ethnic inheritance due to the prevalence of certain diseases within the group, should realize that all ethnic groups, due to the founder effect, are susceptible to certain diseases, and that Jews have not cornered the market on genetic disorders.)

But a Jew who discovers that he or she is indeed a carrier should not be coerced or expected to share this information with employers or insurers (see p.6 above) but should share it with a spouse or with an intended or even prospective spouse for the sake of avoiding *teruf ha'daat,* the 'tearing' of one's mind due to the pressures of secrecy and/or the burden of crucial knowledge on which one has chosen not to act. Spouses or potential spouses who have reservations about being tested themselves for fear of discovering that they are carriers, or intended spouses who turn out to be carriers themselves, should realize that a marriage in which biological (in contrast to adopted)

children are desired need not end or be called off --that all is not lost-- thanks to the option of PGD (pre-implantation genetic diagnosis) discussed earlier.

If, however, this option of discarding defective zygotes and implanting only healthy eight-celled embryos into the mother's uterus is chosen as a future strategy, both partners should examine the financial costs of IVF (in vitro fertilization) followed by PGD. This discussion may be usefully framed by the Jewish concern with justice, which of necessity requires an examination of social --that is, community-based—needs in their relationship to personal wants.

Likewise, others who know that they themselves are carriers and are contemplating bio-

logical parenthood through the use of donated sperm or eggs (single women, lesbians, gays who make use of donated eggs and then surrogacy, and those confronting issues of infertility in a heterosexual partner) should insist on knowing the carrier status of chosen donors. This is especially important when the donation takes place informally, outside of the context of a donor bank or other 'medical' fertility venue where testing can be presumed to have taken place.

Expectant parents who learn through amniocentesis or CVS (corionic villus sampling) that the developing fetus is affected with one of the fatal childhood *diseases having no known treatment or cure* may consider a therapeutic abortion performed during the first trimester as an act of *rachmanut* [compassion] toward themselves as parents and their unborn child. (Although therapeutic abortions are generally not sanctioned by the Orthodox community, at least one *posek* [rabbinic decisor] , Rabbi Eliezer Yehuda Waldenberg, permits the abortion of a Tay-Sachs fetus under certain conditions.[18])

Compassion is as cherished a value in Judaism as justice; many sources remind us of this.[19] On the other hand, abortion on demand or even discarding particular zygotes **cannot** be considered an option for the sake of sex selection or the selection of other traits, since they do not meet the criteria of untreatable, debilitating disease and immanent, painful death which the values of compassion and avoiding mental anguish both address.

The Jewish understanding of the need for *anava / yirat shamayim* [humility / reverence for God] coupled with the deeply rooted idea that all human beings are created *b'tzelem Elohim* [in the Divine image], should provide a useful context in which to consider decisions about whether to prevent the birth of children with other kinds of abnormalities that can be exposed through genetic testing. We do not know, after all, what God has in store for us or why; we do not know why there is such a marked range in human talent, appearance, length of life, opportunity, etc. The prospect of raising children who can live into puberty or beyond with debilitating conditions such as cerebral palsy, cystic fibrosis, or Gaucher's Disease Type I, especially in this era of prevention through modalities described throughout the paper, can be daunting. In addition, there is the pressure in our culture to strive for perfection.

We are reminded, however, to refer to God as *M'shaneh ha-briyot* [the one who makes creatures different] when seeing someone whose appearance or ability to function does not match whatever has become normative for us. Awareness of these interlocking values can reduce the all too common temptation to strive for a vaguely felt perfection in our own selves or to expect it in others. It can also provide the reflective context needed to 'unpack' this highly culturally determined term, especially as we grapple with the

difference between defect and difference. Bioethicist Glen McGee points out that "a scientifically styled 'perfect society', stratified by genes, makes little sense in a world where genetic variability turns out to be a virtue – and in which specialization and rigidity spell extinction." He also notes the highly cultural component of our ideals of perfection, for example, intelligence.[20]

Prospective parents should also realize that it is part of the human condition for a certain amount of risk –to one's personal identity, one's sense of entitlement, one's well-being— to come with the act of procreation. In fact, relatively few of life's surprises can be dismissed through genetic testing. Perhaps for Jews the concept of *k'dusha* [holiness] provides the only reliable way of keeping the wolf from the door – keeping our particular struggles from over-whelming us from time to time. When we set aside certain times, spaces, ideas, feelings, and deeds as holy, we allow ourselves to demarcate, to separate reality into more manageable portions and give ourselves permission to notice that which transcends ordinary experience.

K'dusha also seems to be our best defense as Jews against the secularizing of, if not routinizing of, our own biggest decisions or revelations. For example, expectant parents should not let the now common prenatal practice that calls for on-the-spot informed consent for genetic testing rob them of a sense of the holiness of life that is developing within the mother's body. Collecting data on short notice about a growing fetus, without allowing thoughtful weighing of its subsequent therapeutic use, should not be acceptable to us as we strive to make room for holiness.

In 1951, Mordecai Kaplan produced a small book entitled *Know How to Answer: A Guide to Reconstructionism* in which he highlighted a number of the values discussed above as contributors to the vitality of Judaism. He also made the important point that these values are not 'inheritable' from parent to child. Indeed in answer to the question, "Is Jewish birth the basic qualification for being a Jew?" Kaplan answered:

> No. The basic qualifications for being a Jew are (1) …the acceptance of the Jewish people in the past, present and the future as one's own people; (2) …the conviction that the Jewish spiritual heritage affords inspiration for living, and (3) participation in Jewish life, i.e., sharing in those activities which help to insure the perpetuation of the Jewish people and the advancement of its civilization. These qualifications, and not Jewish parentage, have been stressed in the bulk of our tradition .[21]

Yet, as noble as these qualifications sound, those who would lead the Jewish people in the strengthening and further growth of Judaism should make sure that they do not entirely disparage conceptions that tie it to a physical inheritance passed down from one generation to the next. To abandon those notions entirely and not advocate for their diagnostic use in the sphere of preventive medicine would perhaps be akin, if not to throwing out the baby with the bathwater, at least to throwing out too much bathwater for the baby's good.

Notes

1. Cheye Calvo and Alissa Johnson, "Genetics Policy Report: Insurance Issues" (Denver: National Conference of State Legislatures, 2001), pp. 4-5.

2. National Institutes of Health, *Understanding Gene Testing* (Washington, D.C.: Office of Publications of the U.S. Department of Health and Human Services, 1995), pp. 9 – 16.

3. Miryam Z. Wahrman, *Brave New Judaism: When Science and Scripture Collide* (Lebanon, NH: Brandeis University Press/University Press of New England, 2002), p. 100.

4. Jewish Family Services Genetic Education and Screening Project, *Do You Know about Genetic Diseases Affecting Jewish Families?* (pamphlet, date of publication unknown)

5. Calvo and Johnson, "Genetics Policy Report: Insurance Issues," p. xi.

6. National Institutes of Health, *Understanding Gene Testing*, p.18.

7. Wahrman, *Brave New Judaism*, p. 97.

8. Risa Davis, Director, Genetic Education and Screening Project of Jewish Family Services of Central Maryland, private conversation, May, 2003.

9. Wahrman, *Brave New Judaism,* p. 102.

10. Ibid., p. 103.

11. Idem.

12. National Institutes of Health, *Understanding Gene Testing,* p. 18.

13. Elliot N. Dorff, *Matters of Life and Death: A Jewish Approach to Modern Medical Ethics* (Philadelphia: The Jewish Publication Society, 1998), p. 153 ff.

14. Karen Litwack, Director, Chicago Center for Jewish Genetic Disorders, private conversation, June, 2003.

15. Hayim H. Donin, *To Raise a Jewish Child: A Guide for Parents* (New York: Basic Books, 1977), p. 147.

16. James M. Gordon, "An Overview of Halakhic Issues Pertaining to Jewish Genetic Disorders," in the "Resources for Rabbis" section of the Chicago Center for Jewish Genetic Disorders website, www.jewishgeneticscenter.org.

17. Idem.

18. Fred Rosner, "Judaism, Genetic Screening and Genetic Therapy", www.us-israel.org/jsource/Judaism/genetic.html. 2000.

19. Donin, *To Raise a Jewish Child*, pp. 37-38.

20. Glenn McGee, *The Perfect Baby: A Pragmatic Approach to Genetics* (Lanham, MD: Rowman and Littlefield Publishers, 1997), pp. 122, 118.

21. Mordecai Kaplan, *Know How to Answer: a Guide to Reconstructionism* (New York: Jewish Reconstructionist Foundation, Inc., 1951), p. 31.

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