

## Jewish Genetics: The Call for Knowledge

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What are your genes telling you? Your g-e-n-e-s. Is Jewish identity wrapped up in our genes? Consider Oswald Rufeisen, born to a Jewish family in a small town near Auschwitz in 1922. He was hidden in a convent during the Holocaust and later converted to Catholicism. As a Carmelite friar, he saved hundreds of Jews from deportation to concentration camps. In the 1950s, in the face of anti-Semitism in Poland, he immigrated to Israel. When he applied for citizenship under the Law of Return, which guarantees immediate citizenship for Jews coming to Israel, the government and later the Supreme Court of Israel, denied his request, on the grounds that by virtue of his conversion, he was no longer a Jew. His application for citizenship would not be fast-tracked, by virtue of Jewish identity. This event of a half-century ago, known as the “Brother Daniel” case, gives us a sense that the question “What makes us Jewish?” is far deeper than just genetics and heritage. Genetic makeup does not

define Jewishness- one's beliefs and behaviors make Judaism a vibrant religion and make one a part of the Jewish people. Geneticist Dr. Harry Ostrer, elaborated on a definition of Jewishness when he wrote: Jews are "a people with a shared genetic legacy, although not all Jews share the same genes. Nor is having a part of that (genetic) legacy a requirement for being Jewish." In the case of Brother Daniel, one can be a part of a shared genetic legacy, but not be a part of the Jewish people. In other words, Genetic material tells us more about the Jewish past than the Jewish present or future.

But remarkably, geneticists can now tell us much about Jewish history, from studying our DNA. Some of their insights made headline news, such as the Y-chromosome study of those men who believed, because they had the last name Cohen, they were descended from the Kohenim, the ancient hereditary Priesthood. Subsequent studies revealed that what was thought to be a marker for Jewish Cohanim was really not unique to Jewish men- it was found in 20% of the non-Jewish male population in Yemen, Iraq,

Oman and Palestine. <sup>1</sup> But as research techniques have advanced, we have been able to see some remarkable things: there IS a particular priestly ( J1) lineage where 46% of the men share a gene back to before the time of King Saul, the first King of Israel.<sup>2</sup> We can tell that the Jewish propensity toward hereditary breast and ovarian cancer, hemophilia and Parkinson’s disease go back to founding events in the time of King Solomon, and that Tay Sachs has been with us since the Babylonian exile. The genetic mutation for cystic fibrosis goes back to the time of Abraham. <sup>3</sup> When Jews settled for the first time in the Rhineland, around the year 800, those diseases migrated and coalesced. Today, 80% of Ashkenazi Jewish men can trace their genes to only seven Y-chromosomal lines!<sup>4</sup> All of that we can determine, by what is inside our DNA! As my Grandpa Max, of blessed memory, would have said, “who’d have believed they could do that!”

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<sup>1</sup> Pg. 96

<sup>2</sup> pg. 98

<sup>3</sup> pg. 71-74

<sup>4</sup> pg. 91

Dr. Edward Burns, of the Albert Einstein College of Medicine, summed it up this way: “Any two Ashkenazi Jews whose great-grandparents lived in Central and Eastern Europe before the war share enough genes to qualify as 4<sup>th</sup> and 5<sup>th</sup> cousins. Any two Iranian Jews whose forebears lived in Iran from the time of Cyrus the Great to the fall of the Shah share enough genes to qualify as third cousins. Jews have characterized themselves as a people, but with these genetic links, they are more like an extended family.”

While Jewish genetics does not foretell the strength and vibrancy of the Jewish community, it does have an impact on the Jewish future. You and I and our children carry DNA that may indicate we are carriers of recessive genes for some 100 genetic diseases. But you don't have to be Jewish to worry about carrying Jewish genetic diseases. Our history, our wanderings, our mixture with other peoples- both long ago and more recently- reminds us that our genes are more about **biology** than **theology**.

This is a message for anyone who plans to procreate with us, our children, or our grandchildren. The key is for any couple to understand their genetic material before passing it along. Many people might think, at first blush, I don't want to know what is in my genetic makeup. Testing is not about getting good news or bad news, but about getting the information necessary to wisely plan for a family. This is not a case of "what I don't know can't hurt me." Knowing means having the widest range of options as one plans their family. Ten years ago, it was possible for geneticists to test for 10 Jewish genetic diseases. Today, a blood test can check for 19. One in three persons of Ashkenazic heritage is a carrier for at least one Jewish genetic disease of those 19. Why should you, or your child, or grandchild, consider being tested? Because carriers exhibit no symptoms or health problems and usually have no known family history of Jewish genetic diseases. You will only know you are a carrier if you are screened, or you have a child born with the disease. Genetic diseases occur in families with not prior history.

There is no treatment for most of these diseases; they can be fatal to the child and life-altering to the family. So for a couple to test before pregnancy opens the full range of options. No one will discourage them from marrying the person they love, or even from having children together. But with the support of genetic counselors and their doctors, they can explore options such as in-vitro fertilization with their own genetic material, fertilizing and then implanting unaffected eggs that have been tested for the disease. Couples can consider using donor egg or sperm from a non-carrier, or adoption. One's options are more limited, if a couple waits until pregnant to do a fetal diagnosis through amniocentesis. Then a couple must make heart-wrenching decisions between carrying or terminating the pregnancy. The most rigid of Orthodox scholars in regard to genetic testing, Rabbi Moshe Feinstein, has written, that to forego genetic testing in favor of placing one's trust in God, is tantamount to closing one's eyes in order to not see that which it is possible to see.<sup>5</sup>In fact,

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<sup>5</sup> Rabbi Moshe Feinstein does not permit abortion, more lenient Orthodox rabbi Eliezer Waldenberg, does.

adds Rabbi David Bleich, an Orthodox medical halakhist, it is like walking into a busy intersection blind. “Turning a blind eye to a danger is not an act of unquestioning faith, but an act of rash conceit.”<sup>6</sup> The knowledge and ability to respond to genetic issues is a gift from God.

But DNA testing is not just a parenthood issue. Last spring, Anne Wojcicki (wo-chick-i) addressed a group of rabbis, encouraging us to encourage you, to consider DNA testing. As the founder of 23andMe, a gene testing company named after our 23 pairs of chromosomes, her vision is to transform our medical future, by giving scientists the greatest amount of DNA data to study illnesses, from heart disease to muscular dystrophy, from diseases that are prevalent in general society to illnesses that are prevalent in certain groups. Through her mail order “spit-and-send” approach, what 23andMe can give you is highly personalized information about diseases you may be a carrier for, or have a pre-disposition toward. It can give you insight about unanticipated drug responses

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<sup>6</sup> Rabbi J. David Bleich, commenting on Feinstein’s *Iggeret Mosheh*, even ha-ezer IV, #10.

because of your genetic makeup, it can supply data for knowledgeable family planning, and ancestry insights. Anne's is not the only company around for testing DNA. There are those who hope that, by knowing our own genetic selves, we can improve the world of medicine and empower people to live healthier, longer lives. When we consider ethnically-Jewish pre-dispositions toward Irritable Bowel Diseases like Crohn's and ulcerative colitis, lactose intolerance and Celiac disease, cancers that affect the prostate, pancreas and colon, hereditary breast and ovarian cancers, mental illnesses, diabetes and heart disease, aren't we in a position to add to the research and the progress in addressing these conditions for ourselves and future generations?

Some of us may hold concerns about the public nature of our genetic information. In 2008, "GINA," the Genetic Information Nondiscrimination Act was passed to protect anyone from being treated unfairly because of their genetic inheritance. And in 2009 laws were passed that say, first, health insurers may not deny or



limit coverage or charge higher premiums based on a person's genetic information (May), and secondly, that employers may not use genetic information to make decisions about hiring, firing, promoting or job placement (Nov.) The concern, says ethicist Dr. Lori Andrews, is not about insurance companies, employers and medical providers, but personal: "How much information do we want and what do you do with it?" How do we prepare people to handle information about diseases that may or may not be deadly? This is not like other medical areas, where there is a clear treatment, this has an impact on self-concept and on relationships with others. It is not a simple blood test."

In the face of those fears, Judaism discourages us from avoiding information, keeping ourselves purposefully in the dark about issues that could effect the well-being of others. It is both a curiosity and a bit frightening to find out what our genetic make-up may be. But to know, is to avoid what can be great heartbreak for the people we love most in our lives. Let me ask you a question:

when was the last time you heard about a child being born with Tay-Sachs, the most well-known of JGD? The Jewish community became aware that the heartbreak of having a child who would suffer seizures, blindness, swallowing problems and die by age 5 was so unthinkable, that they needed to proactively prevent the disease. Routine Genetic testing in 50 cities, at synagogues and JCCs, so reduced the rate of Tay-Sachs, that in two generations, from the 1970s to the beginning of the 21<sup>st</sup> century, it is virtually gone, its incidence slashed 95%. Now, rather than 50 babies born each year with Tay-Sachs, less than 5 are, and most are born to non-Jewish couples who happen to have the mutated gene, but never thought to be tested. Again, genes are not religiously-tied, they are ethnically tied. We think of Tay Sachs as affecting Ashkenazi Jews, but Moroccan Jews, Iraqi Jews, Louisiana Cajuns, Pennsylvania Dutch and French Canadians are all carriers of the recessive gene. Only with knowledge can we respond to real diseases, and their effect.

In one of my favorite movies, Tevye turns to his wife Golda and he says to her, “it’s a new world, Golda, a new world.” Who ever thought that DNA sequencing, could be done, the human genome brought to light? In another decade, we will be able to find out more about ourselves, than we can hardly imagine now. Our tradition teaches us that medical knowledge, is a gift that we should embrace. If we can live healthier lives, create healthier children, can we take that step? The world may be new, but our genes are very old. They tell a story of our history, and our people’s history. You don’t have to have Jewish genes to insure the vibrant future of Judaism. But the future health of the Jewish people may be in your hands. Gut yuntif.