



# AVOTAYNU®

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# How I Have Traced the Beta Thalassemia Trait

by Stanley M. Diamond

The beta thalassemia trait was not identified until the 20th century, and although much has been learned, misconceptions still linger among those not directly affected. Thalassemia comes from the word *thalassa*, Greek for sea, and originally was called Mediterranean anemia.

In an American television episode, a "bad guy" ostensibly was identified and located because he was a carrier of the beta thalassemia trait. The script incorrectly claimed that beta thalassemia was unique to people of Greek origin and that the perpetrator would be taking medication for this condition. In fact, many of the more than 500 million people around the world who carry the beta thalassemia trait come from ethnic backgrounds other than Greek. One in 25 carriers is Italian, others are East Asians, Sephardic Jews, Arabs and others. I am a carrier, and my Ashkenazic Jewish family lived in Poland before emigrating to the United States and Canada.

It is here that my story began, as I attempted to look back from a genealogical viewpoint, identify the source of this gene and reach forward to locate those unsuspecting relatives at risk, who would benefit from knowing our family legacy.

Fortunately, children, like myself, who inherit the beta thalassemia trait (i.e., a single copy of the gene) from one parent live normal lives. Only those children who inherit the gene from both parents have the disease, and until relatively recently, they rarely lived past the second decade of life. If they do have the disease, thalassemia major, the treatment is not, as stated on the television show, simply medication; the standard treatment relies heavily on regular blood transfusions.

To my knowledge, no one in my family suffered from a disease of this nature, so in 1977, I was baffled when doctors at Harvard Medical School were concerned that my nephew's chronic anemia might signify something life threatening. Fortunately, the diagnosis was "only" the beta thalassemia trait. The late Dr. Arthur Cooperberg, then head of hematology at Montreal Jewish General Hospital, explained that it is highly unusual for members of an Ashkenazic family to be carriers of this trait, typically seen in Italian and Greek families. Dr. Cooperberg had excellent scientific instincts and asked to do a full study of our family; we agreed.

Results revealed that all three of my siblings and I, plus 9 of our combined 13 children, were carriers and that our father had passed the gene on to us. We knew

little about our American and Polish cousins since my grandparents emigrated to the United States in 1891 and then to Montreal in 1898. Although we were curious about the source of the trait, and knew the significance to future generations, no one bothered to look further.

In 1977, I had no time for family research, but 14 years later, a letter arrived from a previously unknown paternal relative in Hawaii asking about his Diamond cousins in Canada. Finally, there was someone outside the immediate family to ask, "Do you carry the beta thalassemia trait?" I was semi-retired and ready for the pursuit, so I decided to combine my curiosity with a trip to Hawaii.

While my cousin in Hawaii was not a carrier (research proved negative), I did obtain leads to many more cousins in my father's father's family. When questioned, they all answered, "No, I'm not anemic," or "Beta thalassemia? What's that?" Fortunately, an old address book turned up a Florida telephone number for a distant cousin descended from Hersz Widelec, brother of my father's mother, Masha. After the usual formalities of identifying myself and discussing how we were related, I hesitatingly asked, "Is there any incidence of anemia in your branch?" "Oh, you mean beta thalassemia, it's all over our family."

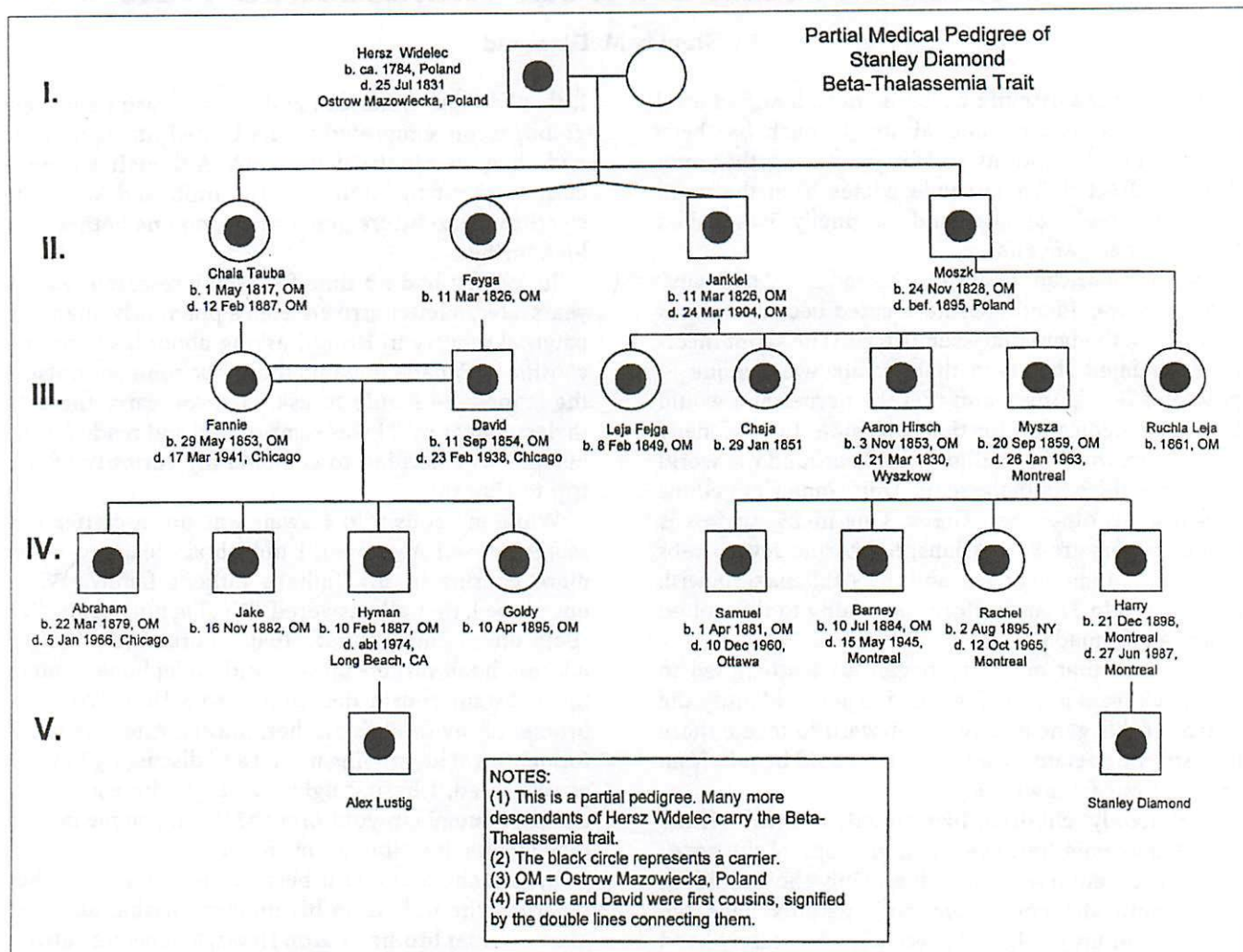
In that one moment it became clear that my father inherited the trait from his mother, Masha, and that Masha's older brother, Aaron Hersz, had been a carrier. While there is only a one in two chance of inheriting the gene from a parent, Masha and Aaron Hersz had clearly done so, and we knew immediately that the source was one of my father's maternal grandparents, Jankiel Widelec, or his wife, Sara Nowes. One telephone call, and the origin of the trait went back to 1826! At this point, I knew where to focus my future research.

Six months later, at the 1992 Jewish genealogy conference in New York, I listened to Dr. Robert Desnick's lecture on Jewish genetic diseases. Desnick, chairman of the Department of Human Genetics at Mount Sinai Hospital and Medical School in New York, didn't mention beta thalassemia in his talk, but his handout indicated that its incidence is so rare among Ashkenazim that no percentage value could be assigned. I asked Dr. Desnick, "If Ashkenazim aren't supposed to be carriers, does that mean if I find others, they will be related?"

Desnick suggested that the first step was to determine if the Diamonds carry one of the more common



## Partial Tree of the Descendants of Hersz Widelec and His Family's Beta Thalassemia Trait



mutations for beta thalassemia or a novel one, unique to our family. He directed me to fellow Montrealer, Dr. Charles Scriver of McGill University, a leader in the study of the beta thalassemia trait. In early 1993, Scriver's research institute received a grant to do DNA screening to determine the exact mutation my family carries.

Soon after meeting Dr. Desnick (but unrelated to that event), I discovered that my family had come from Ostrow Mazowiecka, Poland—Ostrova for short. I immediately ordered Mormon microfilms of the town's records from 1826 to 1865. At the same time, I learned about Michael Richman, an attorney in Washington who also traces his roots to Ostrova. Michael's earlier analysis of the families of the town, along with my follow-up research, enabled me to document my Widelec family from 1760 to the mid-19th century. Less than a year later, the main branches living in the United States had been connected to the earlier family tree. All those who had been saying, "Anyone in the States with the name Widelitz or Widelec is related"

now knew it to be true.

In December 1993, Dr. Scriver faxed me results of the DNA screening. Our family carries a novel mutation, one not described in previous medical literature. This new mutation had been identified only one year earlier from the DNA of a family formerly from Bobruysk, Belarus, now living in Israel. Dr. Ariella Oppenheim's scientific paper announcing the discovery of the novel mutation, had been reviewed and then had been communicated by the very same Dr. Scriver. I telephoned Dr. Oppenheim at the Hebrew University in Jerusalem, and our three-way cooperation was born.

I had asked Dr. Desnick, "If I find other Ashkenazic carriers, will it be possible to find relatives?" Now, with the first DNA test, I had a distant family that genealogical research might never have uncovered.

Five months later, in May 1994, at the Jewish genealogy conference in Jerusalem, I met my genetic cousins and learned about their family history with the hope of "geographically triangulating" (finding our common ancestor) the origin of the mutation. I was



curious to know if they had taken any steps to alert distant branches to the dangers associated with being a carrier of the trait. They had not; like many families, a combination of embarrassment, laziness or ignorance had led to their inaction.

To my continued good fortune, the guest of honor at the 1994 conference was the late Professor Jerzy Skowronek, director-general of the Polish State Archives. Skowronek fully understood the nature of my pursuit and the potential for both humanitarian and scientific benefit. He offered his full cooperation and invited me to come to Poland to continue my research. But, before traveling abroad, there was still research to do on this side of the water.

In November 1994, under the tutelage of Gary Mokotoff and Eileen Polokoff, I spent a week in Salt Lake City searching the microfilms of Jewish vital records from towns near Ostrów Mazowiecka for other branches of the family. This totally fruitless effort prompted me to write a number of genealogists with an interest in the same towns, seeking ways to do joint research and to avoid senseless duplication of effort.

Eventually, this outreach led to the creation of Jewish Records Indexing-Poland, the initiative that has already had a dramatic impact on the method of researching Polish-Jewish family history. Aside from its benefits to the genealogical community, the scientific community has recognized its potential value for genetic and medical research relating to Ashkenazic populations.

At the June 1995 Jewish genealogy conference in Washington, DC, I finally met Michael Richman, the expert Ostrova researcher with whom I had been corresponding since October 1992. Since we both had been in touch with other Ostrova researchers, the 1995 conference was an ideal time for us to meet and examine ways to share research. During the meeting, I mentioned Professor Skowronek's offer of help. This encouraged Michael to accompany me on a research trip to Poland.

### **First Trip to Poland, October 1995**

One month before we left for Poland, Michael suggested that we ask Director Skowronek for permission to copy the index pages for the years of Ostrów Mazowiecka records not filmed by the LDS. Michael knew that two weeks would be barely enough time to scratch the surface; there would be tens of thousands of records and many hundreds to extract for information about our extended families. Although I considered Michael's suggestion to be wishful thinking, 17 days before we set out, I faxed Skowronek and asked if we could create a database of the town's records to enable us to identify rapidly those requiring specific attention. To my surprise and gratification, Skowronek agreed, and the archives started photocopying the

index pages. We hired a travel guide/professional researcher recommended to us by Fay Bussgang to computerize and transliterate the Russian-language indexes, so that by the time we arrived, there was enough data to give us a good start. At the end of two exhausting weeks, we had made a major dent in our research. Although it pales beside the size of my family tree now, that first trip to Poland allowed me to identify 15 additional branches to be researched and whose descendants—if they had survived the Holocaust—had to be warned about the trait.

When we returned home, we shared the good news with our fellow researchers, members of the new Ostrów Mazowiecka Research Family formed at the Washington conference, who had helped fund the database.

Three months later, I handed a hard copy of the database to Professor Skowronek in his office in Warsaw. He was amazed by the finished product; it turned out to be the first step in ultimately reaching the agreement to index the Jewish vital records of Poland that had not been filmed by the Mormons. After that, in support of my efforts to document carriers in my family, the Polish State Archives agreed to microfilm all the Books of Residents of the town; all the post-1865 birth, marriage and death records not filmed by the Mormons; and all the 1826–92 marriage supplements that are not part of the Mormon filming. As a result, the Ostrów Mazowiecka Research Family has created the most complete set of indexes and extracts ever assembled for a town in Poland.

### **What Is Different?**

I have mentioned family lore, archival records, networking—all part of the genealogist's normal research routine. So if that's the case, then what has made my quest unusual? What can others learn from my efforts to find and document carriers of the beta thalassemia trait in my family? How is genealogical research with a medical/genetic focus different from a typical family history project? Following are a few examples and ideas for starting family medical and genealogy research.

**Create a Web Page.** The potential for networking has exploded as a result of the Internet, so create a web page. Mine, [WWW.DIAMONDGEN.ORG](http://WWW.DIAMONDGEN.ORG), has generated many messages from other beta thalassemia carriers, especially those whose families do not fit the usual profile and, therefore, are not expected to have the trait—people from England, Scotland, Wales or Australia who, to their knowledge, do not have anyone in their trees who would be a possible carrier. Most want to share their surprise with me and later say thanks for inspiring them to search for unsuspecting carriers in their families. In addition, I regularly receive messages



asking about leads on other possible Ashkenazic carriers or contacts who might be a source of information down the road.

**Support of the Jewish Genealogical Community.** Post a message on a newsgroup, and thousands of people become your potential eyes and ears. Ask a question; the typical response is detailed and useful.

**Involve Archivists.** Polish archivists have been allies and have been another source of information and networking. I was invited to write an article for the newsletter of the association of civil records offices across Poland. Professor Skowronek wrote the Belarus archives on my behalf.

When research is particularly interesting or has far-reaching consequences, magazines and newspapers may take notice. As president of the Montreal Jewish Genealogical Society, I have had many calls from journalists writing the basic "how to start your family tree" article. When the conversation shifts to my personal interests, the medical editor is often the next one to call. Two years ago, a Canadian television network made a documentary about my research.

When I explain my research, cemeteries have been forthcoming with maps and databases. This is not surprising. When research involves life-threatening situations or the health of future generations, a cooperative response almost always is forthcoming. Enhanced credibility, however, is not automatic; time, effort and patience brings all the pieces together.

## Obstacles

Many resources exist for assistance and guidance. On the other hand, the greatest barrier sometimes is the relatives you know and the families you have just found. People ask, "Why are you doing this?" A genealogist's fascination with family history is one thing, but answering the question "why?" when it involves genetic or medical matters may ring alarm bells among some folks.

Last year, I discussed this problem with genetic counselor Shelly Crane. She, too, has been frustrated both by her own uncooperative family members and those of clients who have been secretive about genetic and medical matters. Shelly wrote:

They don't talk about it and it's sad. Every now and then a family will communicate and work together, but often the opposite happens and they grow apart. When there is a genetic disorder or trait in a family, it can have a profound impact on one's psyche, creating powerful reactions including denial and family tension. Some individuals and even the entire family unit may take it to mean they are defective and feel great shame and guilt, particularly if they passed it on to subsequent generations. For others, it's an opportunity to grow, take charge of their lives and help others.

Shelly added:

Our genes define who we are from the moment of conception, and it goes to the very core of our being. So, it's not surprising that families have intense reactions.

I have no perfect solution for surmounting a wall of silence, fear or antagonism. Just be as diplomatic as possible with a direct, carefully crafted answer, one that invites cooperation as opposed to "never bother me again." It doesn't hurt to make it clear from the start that you're not after money. Unless you know and can define your objectives, don't expect others to understand what you're doing. In my case, I say, "I believe I have the obligation to find and alert unsuspecting carriers in our family about the potential dangers of the beta thalassemia trait to our future generations." Be able to explain details about the medical condition or genetic trait that is the basis for your reaching out. Prepare a document that can be used to follow-up verbal communications, and attach articles and support letters from the medical community. Communicate how your research will benefit all members of your family and their future generations. Use terms people easily understand, such as "life-saving" or "trying to minimize the inheritance of a genetic disease in future generations." Tell what you expect to do with the information you gather, how it will be communicated to family members or shared with medical and scientific researchers. And, of course emphasize that you will respect any confidence entrusted to you and will request permission before disclosing anything personal.

## Building My Beta Thalassemia Tree

Before I could use any of the techniques just outlined, I had to build my family tree. Here are a few highlights.

In 1992, I knew one of my great-grandparents carried the trait, but I didn't know if was Jankiel or his wife, Sarah Nowes. To go back another generation, I needed to find a carrier among the descendants of a sibling of either Jankiel or Sarah. My initial research of living Nowes descendants indicated that Sarah's brother, Szmul, was the only one with progeny; two others had died young, and two brothers seemed to have disappeared. If Szmul wasn't a carrier, the Nowes trail would end right there.

Widelec family research was frustrating for other reasons. Interviews with hundreds of descendants of the two surviving brothers of my great-grandfather, Jankiel, all ended the same: "No anemia; no beta thalassemia." Two years after going to Poland and identifying the families of Jankiel's two sisters, Chaia and Fejga, I still had not found any of their descendants. Then, in January 1998, Nadine Cherney visited Waldheim Cemetery in Chicago. Nadine and I have cousins in common, so she sent me the partial maps



she received. Two names jumped out, David and Fannie Lustig. For three years, I had been looking for records for David and Feige Lustig, first cousins who had married in Poland. I called the cemetery and confirmed that the fathers' names on the gravestones were the ones I had sought. Because David and Fannie's grandson was paying for permanent care, I was able to find him in minutes. Soon after, I heard the news: beta thalassemia trait is widespread in the Lustig clan. Because first cousins Fannie and David were also first cousins of my grandmother, Masha, it was finally the breakthrough I'd been waiting for.

Finding David and Fannie's family was one thing. Since they were first cousins, I still needed to know which of Jankiel Widelec's sisters carried the trait. Was it David's mother, Feyga Widelec Lustig, or Fannie's mother, Chaia Widelec Bengelsdorf? I also wondered if both were carriers and if some of their children had inherited the gene from both parents, two doses of the gene that would have resulted in the fatal disease, thalassemia major. Survival of a number of children born close together seemed to rule out thalassemia major. Moreover, stories of young children dying in Poland were not part of family lore.

I knew that Fannie Lustyk's sister, Musia, had married Calka Dmocher of Andrzejewo, a village 20 km east of Ostrów Mazowiecka, but it wasn't until Jewish Records Indexing-Poland completed the indexes to that village's records that everything fell into place. The indexes include fathers' names, so I was able to identify three children of Musia and Calka, and I found the record of daughter Golda's marriage to Alter Lapka. I later learned that Golda and Alter Lapka had six children. Now, all I had to do was find my Lapkak family, direct descendants of Fannie Lustyk's sister, Musia.

Fortunately the online database of New York cemeteries includes three sections associated with Andrzejewo. The Montefiore Cemetery has three Lapka burials. Before long, I was talking to newly found Lapka cousins and learning that they, too, carry the trait. They also tell tales of misdiagnoses and incorrectly prescribed iron. Since the Lapka's inherited the trait from Musia Bengelsdorf, the sister of Fannie, I now know it was Fannie and Musia's mother, Chaia, who was a carrier and not Chaia's sister, Fejga Lustyk.

What had happened to the rest of the Dmocher family, the three brothers of Golda Dmocher Lapka? The Lapka family had the answer. After arriving in the U.S., all the Dmocher brothers took the name Goldberg! I hit a plateau in my research, filling in other twigs in the branches I knew were carriers. Then came a huge breakthrough.

Imagine your name is Schwab, but you have been told that the name in Poland was Żaba. Imagine my fruitless efforts searching for descendants of a distant

cousin, Chana Rywka Widelec Sztaba, not knowing the Sztabas had first become Cohen and then Schwab. Luckily for me, in July 1999, a curious historian named Orrin Schwab decided to research his family on the Internet. Orrin discovered the JewishGen Family Finder. No one was researching Żaba, so he printed and checked 37 pages of names associated with Lomza. The closest match was Sztaba. Schwab then searched the JewishGen Archives for Sztaba and my post from September 1997 popped up. The subject line was: "Anemia, or is it beta thalassemia?" Orrin had hit pay dirt. Orrin's family has many beta thalassemia carriers. He not only had confirmed the family's original surname, he also discovered me and the thousands of his cousins I had documented.

We knew we were related, but how? The further back we go, the greater the possibility of moving the source of the trait to an earlier generation. The clue was Orrin's grandmother's unusual name, Chaszka Cwejbak. Using the indexes to the Books of Residents of Ostrova, I found the right family grouping. The family name was Cwejbak, with children Chazka and Mnucha. But the mother's name wasn't Leah, as the Schwabs had told me. The records listed her as Ruchla Leja. Now, things got very exciting. I had a Ruchla Leja on my family tree—but only identified by her 1861 birth record and her father's and mother's names. I had no later records indicating what happened to her. If this were the same Ruchla Leja, it would be a breakthrough. With a quick call to a very cooperative archivist in the Pultusk branch of the Polish State Archives, I had the answer: Ruchla Leja's father's name in the Book of Residents was listed as Moszekish, the brother of my great-grandfather. Ruchla Leja was my grandmother Masha's first cousin.

I now knew that another large branch of the Widelec family were carriers. It told me that my great-grandfather, Jankiel, had inherited the trait from his father, Hersz Widelec (born 1874), or his wife, Gutka. By the process of elimination, I concluded that Hersz was the carrier. Gutka was one of four sisters; my cousin and fellow researcher, Judie Ostroff Goldstein, has been researching Gutka's sisters' descendants for as long as I have been building my family tree. Since the chances of inheriting the trait are one out of two, statistically speaking it would have been very probable that Gutka's sisters—if they had been carriers—would have passed the trait to a number of their many children. There is, however, no incidence of the beta thalassemia gene in any of their descendants.

#### **Are All Widelecs Related?**

Earlier I mentioned how I had assumed that everyone with a surname derived from Widelec likely were related to my Ostrova family. I still had no reason to



change that assumption. What I didn't know was my relationship to what appeared to be the two other Widelec families I found in records in other towns south and southeast of Ostrova. Many of the early 19th-century given names matched, and the distances are not great; a connection seemed highly likely.

Over the years, I have spent considerable time and more than a few dollars trying to find the records that would connect me to these families. Even after JRI-Poland indexed many of the records for these towns, the connections still eluded me. It appeared that I might never be able to find documentary proof of a relationship. So two years ago, I took my research to the next logical step. I arranged for DNA samples from direct male descendants in each of the three branches and submitted them to Family Tree DNA in Houston, Texas. The goal was to see if we are related genetically, and, if so, to determine how long ago our most recent common ancestor lived.

Results revealed a relationship between the two other families, but not to mine. Obviously, I was disappointed, but good researchers will all tell you that a solid negative can be as good as a positive. In this case, the DNA results enabled me to remove the other families from my research. Instead, I can now rededi-

cate myself to further exploration of the records in the area where I know my family lived. I hope to identify yet undiscovered branches, those likely descended from unknown sisters of my great-great-grandfather, Hersz Widelec (1784–1831), the earliest known carrier of the trait.

People ask what my ultimate goal is. I have no simple answer, but if I want to dream I guess the response should be, "Until I'm sure I've contacted every small branch of the family I know and find the connection between my family and the family from Bobruysk, my project won't be complete."

It may never happen, but it won't be for lack of trying.

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*Stanley M. Diamond, winner of the 2002 IAJGS Lifetime Achievement Award, is founding president of the Jewish Genealogical Society of Montreal and executive director of Jewish Records Indexing-Poland. His interest in genealogical research related to genetics ultimately led to the creation of JRI-Poland. He is the genealogist for the international team doing research related to his family's novel mutation of the beta thalassemia genetic trait and is coauthor of a scientific paper related to the project.*