

THE JEWISH CHRONICLE

Yahrzeit weekend to address genetic disease screening

by [Lee Chottiner, Executive Editor](#)

01.22.14 - 03:20 pm

Still dealing with the loss of their son Mikey 10 years after his untimely death, Nina and Danny Butler have found what is for them a meaningful way to honor his memory.

The Mikey Butler Yahrzeit Weekend, which will run from Jan. 31 to Feb. 2, is a series of discussions with medical experts dealing with the sensitive subject of screening for one of 19 known Jewish genetic diseases. One in four Ashkenazi Jews is a carrier for at least one of the diseases.

Professors and clinicians from New York and Pittsburgh are expected to attend, speaking to audiences of students, parents, young professionals and medical professionals.

Yeshiva University, Mikey Butler's alma mater, and its medical school, Albert Einstein College of Medicine, are providing speakers for the weekend. The two institutions support the Program for Jewish Health, which provides genetic screening and information on genetic health regardless of cost or other hurdles.

"We wanted to do something constructive and positive with the pain, and that's where the idea of teaming up with an institute Mikey had an affinity with [Yeshiva] came to mind," Nina told the Chronicle.

But the co-sponsorship of virtually every major Jewish organization in the city and suburbs has also overwhelmed the longtime Squirrel Hill couple.

"What ended up being a huge comfort was how easily we were able to get so many different organizations and individuals and groups excited about partnering with us," Nina said.

The Jewish Federation of Greater Pittsburgh and its divisions, Jewish Healthcare Foundation, Jewish Women's Foundation, Victor Center for Jewish Genetic Diseases, Jewish Community Center, Moishe House, Repair the World, J Grads Pittsburgh, Poale Zedeck, Shaare Torah, Young Israel, Kether Torah, Kollel, Yeshiva, Hadassah, National Council of Jewish Women, Hillel Academy, Community Day School, Beth El, Temple Emanuel, Temple Sinai, Beth Shalom, Rodef Shalom, Adat Shalom, Friendship Circle, Hillel Jewish University Center and National Council of Synagogue Youth are among the co-sponsors.

Rarely do so many Jewish organizations from so many divergent backgrounds come together for a single purpose. And the Butlers are keenly aware of it.

“From the perspective of having recently completed a study of Jewish community organization in North America, I have deep appreciation for the uniqueness of Pittsburgh’s community, and our willingness to collaborate,” Nina said.

Frank Michael “Mikey” Butler, died Jan. 26, 2004, following a long and very public battle with cystic fibrosis. He was 24.

His battle with CF, one of the 19 genetic diseases afflicting Ashkenazi Jews, inspired a nationwide campaign in his name called a “Mitzvah for Mikey.” Yeshiva University president Rabbi Norman Lamm personally conferred a bachelor’s degree in political science and business on Mikey in a surprise, private ceremony at Pittsburgh International Airport.

Since his death, the Butlers have coped with the loss in different ways

“I literally go all over the world and talk to Jewish groups [about genetic diseases]. I hit 40 college campuses last year,” Danny said.

Nina chose a different route.

“The way I handled it was to put together something for the community and do some community outreach,” she said.

Result: The Yahrzeit weekend.

The Butlers credited the Victor Center and Dodi Roskies for inspiring the weekend, as well as Dr. Harold Weisenfeld for his assistance in bringing UPMC Magee as a co-sponsor.

Here is the lineup for the weekend:

- “How Jewish Do You Have To Be,” a continuing medical education symposium, Friday, Jan. 31, 7 to 9 a.m. at the UPMC Magee Auditorium with Dr. W. Allen Hogge, chair of the Department of Obstetrics at UPMC Magee, Dr. Susan Klugman, medical director for the program for Jewish Genetic Health at Yeshiva/Einstein; and Rabbi Levi Langer, dean of Jewish studies at the Pittsburgh Kollel Learning Center;
- “Shabbat dinner: Taking A DNA Selfie,” Friday Jan. 31, 6:30 p.m., at Congregation Poale Zedeck, dinner included, featuring Klugman; Dr. Nicole Schreiber-Agus, assistant professor of genetics, obstetrics and gynecology at Einstein; and Chani Wiesman, a genetic counselor at Montefiore Medical Center in New York;

- A Melava Malka on the importance of genetic screening, Saturday, Feb. 1, 8 p.m., at Poale Zedeck, with Schreiber-Agus and Wiesman;
- “Practical Genetics: Myths Debunked,” Sunday, Feb. 2, 9:30 to 11 a.m. at the JCC in Squirrel Hill, with Schreiber-Agus and Wiesman; and
- “The Skinny on your Genes,” Sunday, Feb. 2, noon, with complimentary lunch, with Wiesman.

Contact Nina at ninasbutler@gmail.com for more information about the events.

The Butlers said the program would provide information about genetic screening, not guidance on how to use it.

“We are not saying anything about when to test and what to do with those results,” Nina said.

They see the weekend as a way of “paying forward” to the next generation, in which the Butlers have a vested interest.

“We’re the healthy grandparents of four healthy grandchildren,” Nina said.

“Two of them are named after Mikey,” Danny added.

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