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New sarcoma cancer foundation named for Jewish 'Oma'

by arno rosenfeld , j. correspondent

During his wife's recent battle with cancer, Gary Wiener had a lot of trouble finding information and support.

Sarcoma, the type of cancer Linda eventually was diagnosed with, is so rare — accounting for less than 1 percent of all cancer diagnoses nationwide — that there were no major foundations or comprehensive online resources.

One website had some pretty good information, but the initiative behind it had just gone on hiatus when Linda died at age 60 on April 16. So the family's question became: Without any major foundations out there, what beneficiary should be listed at the end of Linda's death notice in J.?



Gary and Linda Wiener

Gary Wiener, a San Jose resident and the executive director of the Jewish Sports Hall of Fame of Northern California since 2008, created a new entity on the spot. The first name he chose — the Linda Noack Wiener Liposarcoma Research Foundation — was "too clinical," Wiener said in hindsight, and that wasn't Linda's style.

Less than two weeks later, the venture had a new name, the Sarcoma-Oma Foundation, drawing on what Linda's grandkids called her, Oma, the German and Dutch word for grandma. "This term was very important to Linda," Wiener said. "Her dad was from Holland, her mom from Belgium, and they met at Westerbork," a Nazi detention and transit camp in Holland during World War II.

Linda was diagnosed with breast cancer in May 2013, Wiener said, but five months later it was discovered that she actually had liposarcoma (a malignant tumor that arises in fat cells in soft tissue) in her abdomen.

Shortly after she died, one of her grandchildren, 7-year-old Katie, wrote a heartfelt piece that now appears on the foundation's website. "My Oma was so special to me ... She made me feel special every time I was with her. She called me Cookie, and that made me smile," Katie wrote. "April 16 was the saddest day ever. My Oma passed away. It's not fair to me that good people die ... She [gave] me a necklace that she wore which says 'Oma' on it. I plan to wear it every day." (To read more, visit <http://www.sarcoma-oma.org>.)

The Sarcoma-Oma Foundation is being run by Wiener, who certainly has his hands full these days. In addition to planning a January 2016 induction dinner for the NorCal Jewish Sports Hall of Fame, he also runs the event planning business Pinnacle Production Group. He has scaled back a bit on his Pinnacle work and is now devoting about half his working hours to the foundation and its initial lineup of fundraisers.

The first will be a 4k dog walkathon in Atherton on Oct. 11, the second a one-hour spin cycle session led by home run king Barry Bonds in Corte Madera on Oct. 17, and the third a gala in the Grand Ballroom of the Fairmont San Francisco on Nov. 7.

"I spent a good part of my career being very reluctant to ask anybody for a favor," said Wiener.



Linda Wiener was known for her positive spirit.

Not anymore. Thanks to connections he, Linda and two children who work in the entertainment industry made, Wiener has secured not only Bonds, but also actor Malcolm McDowell ("A Clockwork Orange") to host the Nov. 7 gala, actors Sarah Rafferty ("Suits") and Joe Manganiello ("Magic Mike") to do promotional videos and Monica Potter ("Parenthood") to do social media.

For the Bonds event, front-row cycles cost \$350, while others will go for \$150 for the first 10 buyers and by auction after that. Gala prices start at \$250 for individuals and \$5,000 for a table.

Wiener's goal is raise some \$250,000 this year for the foundation, which already has a good-looking website and a high-caliber advisory board that includes oncologists at the Stanford School of Medicine, Harvard Medical School and the University of Texas MD Anderson Cancer Center. The foundation's nonprofit application is pending.

According to the website, an estimated 1.7 million people in the United States will be diagnosed with cancer in 2015; of those, just 12,000 will be diagnosed with sarcoma.

One goal of the foundation, Wiener said, is to provide dependable information and support to sarcoma patients and their loved ones. Not only is sarcoma information scarce, he said, but most of it tends to be research-oriented (with lifespan data that is often scary) rather than practical and supportive.

"The method of communication in the oncology world leaves a lot to be desired," Wiener said. "There are things I learned the hard way, in terms of access to treatment and ways to cope with treatment, that you shouldn't have to learn the hard way. Someone should tell you the day you're diagnosed."

To help give people a template for guidance that the Wiener family never had, the Sarcoma-Oma website features advice for those who are just diagnosed and informational videos from doctors — with more to come as the foundation grows.

Another main function of the foundation, Wiener said, will be helping sarcoma patients pay travel expenses to one of the five U.S. medical facilities specializing in sarcoma treatment (in New York City, Houston, Boston, Denver and Santa Monica).

Though Wiener is working hard, and mourning at the same time, he said much of the passion behind the foundation comes from Linda's community connections and the way her positive spirit touched people. A Fairmont Hotel employee for 15 years, involved in event planning and catering, Linda oversaw dozens of Jewish weddings and bar and bat mitzvahs.

In fact, some of the teens whose celebrations Linda helped plan are putting on a Sarcoma-Oma fundraising talent show at Palo Alto High School in the spring.

"Linda was a joy," said Peter Gold, one of the high school students planning the event. "Every time you were with her she made you feel better about yourself."

Gold still marvels at how Linda kept working on his sister's bat mitzvah after she was diagnosed with cancer, and that she always cared more about others even as she was battling cancer.

So when Wiener approached him about putting together a fundraiser with other teenagers Linda had worked with, Gold didn't hesitate. "Linda made my bar mitzvah the best day of my life," he said.

Sarcoma-Oma Foundation resources and event listings at <http://www.sarcoma-oma.org>
 For more information, contact Gary Wiener at (408) 374-1600 or gary@sarcoma-oma.org