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Column: She weighed 85 pounds and didn't know why. Through persistence and some medical sleuthing, she found out why



Geneviève Jacobs makes an appeal for more personalized immunology research at a symposium she hosted Nov. 8 at the La Jolla Institute for Immunology. Sitting in the front row are her husband, Paul Jacobs, and his parents, Irwin and Joan Jacobs. (La Jolla Institute for Immunology / Melissa Jacobs)

Self diagnosis leads Geneviève Jacobs to champion research and treatment of autoimmune system malfunctions

By DIANE BELL COLUMNIST



The petite woman with wavy, brown hair stood at the lectern sharing the story of her personal medical detective work — going from doctor to doctor, specialist to specialist and doing her own research to diagnose her debilitating condition.

After years of excellent health, her joints had suddenly started aching when she was in her late 30s. She lost her appetite. She suffered brain fogs and was in a chronic state of exhaustion. Small tasks required a huge amount of effort. There was no obvious trigger.

"I weighed 85 pounds. My whole body hurt, and I couldn't think anymore. I was desperately trying to get some help and was wondering what to do to feel better. It seemed like nobody could help me," said **Geneviève Tremblay Jacobs**.

The former pharmaceutical sales rep, and oceanographer by training, from Montreal, Canada, was found to have a high ANA (antinuclear antibodies) count, indicating that her immune system had launched a misguided attack on her own body. So she was put through several tests for specific autoimmune diseases.

The results came back negative. Rheumatologists finally suggested she wait and be re-tested in a few years. Maybe then they could detect a cause. Meanwhile, Jacobs pored through medical data in search of symptoms similar to her own. She came across an article about mercury poisoning.

Her rheumatologist dismissed the idea and didn't see a need to test for it. But eventually she got tested and the report came back positive. The level of mercury in her body was dangerously elevated and certainly high enough to compromise her immune system and trigger a toxic reaction.

But where had the mercury come from? She wasn't living close to a source of mercury contamination. As a non-meat eater, Jacobs diet included a lot of fish. However, she avoided swordfish and tuna, associated with retention of heavy mercury, eating them only sporadically.

She did dine out a lot, though, and frequently ordered salmon and sushi. The light dawned when she discovered that farm-raised salmon, common restaurant fare, often are fed a diet of fish-based pellets — including fish that retain mercury.



Geneviève Tremblay Jacobs is a newly added board member of the La Jolla Institute for Immunology, founded 30 years ago. (Courtesy photo)

Her medical quest eventually took her to Cleveland Clinic doctor **Mark Hyman**, who tested her for Lyme disease. The results were positive. "I didn't recall a tick bite," Jacobs said, but the Borrelia bacterium's DNA was found in her blood.

Hyman put her on an anti-inflammatory diet that excluded dairy products, sugar, soy, gluten — and fish. She ate organic vegetables, non-processed foods — and meat. She also underwent 70

hyperbaric chamber oxygen treatment sessions, ozone therapy, hyperthermia treatment for Lyme disease, chelation therapy for mercury poisoning and took antibiotics.

Slowly, her weight, her health and her energy returned. To her surprise, last May, three years after she started, she tested negative for Lyme disease and the antinuclear antibodies (ANA) no longer were detected.

Jacobs' own experience instilled a thirst for information about the body's autoimmune system and a host of maladies that could be associated with a compromised immune system.

She toured the nonprofit La Jolla Institute for Immunology in UC San Diego's Research Park and talked to its researchers. When asked to join its board of directors nearly two years ago, Jacobs agreed.

Her mission is a practical one: to explore a more holistic approach to healing — one that combines traditional medical treatments with so-called alternative medicine. She also wants to bring in experts and researchers from around the globe to pool their knowledge and share their immunology research to get potential treatments out of the labs and available to people in need.

Jacobs is in a position to help, having married **Paul Jacobs**, former CEO of Qualcomm and son of its co-founder, **Irwin Jacobs**, and his wife, **Joan**.



The Jacobs family, from left, Paul, Geneviève, Irwin and Joan, join Mitchell Kronenberg, president and chief scientific officer of the La Jolla Institute for Immunology, at a Nov. 8, 2019 conference centering on autoimmune disease research. (Courtesy of La Jolla Institute for Immunology / Melissa Jacobs)

Theirs was a Cinderella-style meeting at the Montreal Grand Prix. The French-speaking Canadian was not familiar with the Jacobs name and the telecommunications empire the family had helped found.

Paul, who separated from his first wife in 2013, later proposed to Geneviève in front of the Museum of Contemporary Art San Diego in La Jolla, and they married in 2016.

Geneviève emphasizes that the Institute for Immunology work is her project, but she is grateful for the support of her husband and her in-laws. They were sitting in the front row supporting her as she delivered a heartfelt appeal at a symposium that she had organized on Nov. 8.

Called the Tremblay-Jacobs Symposium, it was devoted to human autoimmunity and brought together experts from various institutions to share their research on autoimmune-linked maladies and answer questions from the public.

The institute made waves when Rancho Santa Fe millionaire entrepreneur **Ralph Whitworth** donated \$10 million to fund lab research there in conjunction with UC San Diego to pioneer

personalized immunotherapy research. He was hopeful of finding a cure for his own rare form of cancer.

John Major, institute board chairman emeritus, estimates that Whitworth prolonged his life by a few years through his innovative treatment efforts. A year before he passed away in 2016, he was in the news for hiring the Rolling Stones to give a rare private concert for his friends at the Belly Up Tavern in Solana Beach.

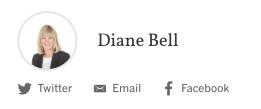
Jacobs admits she gets incensed that research is bottle-necked in laboratories because, while there are plenty of lab rats as test subjects, there are few humans. Rheumatoid arthritis has been cured in rats numerous ways, but those cures don't transfer to people, she argues.

More human subjects need to participate in the research, treatment needs to be personalized and specialists need to emerge from their niches to explore multiple approaches and solutions with other researchers.

Expanding the Institute for Immunology's faculty to be able to do this is her immediate mission.

"We can cure many cancers. We can stabilize HIV," she says, but autoimmune diseases are not being cured.





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