

The Modell's Mission



An Interview with Vicki and Fred Modell, Jeffrey Modell Foundation



Fred and Vicki Modell and Jeffrey (upper right)

FOUNDATION BRIEF *The Jeffrey Modell Foundation (JMF) was created after one family's personal tragedy inspired them to help others. When Vicki and Fred Modell lost their son, Jeffrey, to Primary Immunodeficiency (PI) disease, they were determined to help prevent this pernicious illness from claiming the lives of any more children. Their commitment led them to establish a unique organization dedicated to finding a cure for this life-threatening disease, which afflicts at least 500,000 people in the U.S. alone, and 10 million worldwide.*

They have been tireless in their efforts to help other families who have children with genetic immunodeficiencies and to raise awareness of these diseases by testifying on Capitol Hill, and speaking nationwide and before the E.U. Parliament. In addition, they have funded research and opened clinics around the world.

JMF has developed a global network of specialized centers for diagnosis, clinical care, and research to find treatments and cures for primary immunodeficiencies. Families in the U.S., Canada, Europe, Latin America, the Middle East, Asia, and Africa have found comfort in the expert care they receive at these facilities, as well as through JMF K.I.D.'s Days, workshops, and the JMF hotline and Web site (www.info4pi.org).

The Modells have also successfully testified before Congress on numerous occasions and sponsored physician education conferences in cities around the world.

Can you share your personal story?

Vicki: Jeffrey was born in 1970, and he appeared to be a perfectly healthy baby. But when he turned nine months old, he developed a fever of 104 degrees and was slightly jaundiced. We rushed him to the pediatrician, and he was immediately hospitalized. Within three days, he was diagnosed with Hypogammaglobulinemia. While the diagnosis was certain, the prognosis was uncertain. The physician said they didn't know that much about the immune disorder, but recommended that we not put him in situations where people might be very sick.

Jeffrey continued to grow normally and was fairly healthy until we put him into a nursery school program, which is when he started to develop regular infections and began missing more school than he attended. Fred and I were scared, but we decided we would work cautiously to give him the most normal life we could.

Jeffrey's disease got worse when he was 13 years old, a development that is common with many chronic diseases. It reached the point where he was ill more days than he was well. His hospitalizations became longer and more serious. There were probably seven to ten times when we were sure we were going to lose him during the night, and every time he pulled out of it.

When he was 15, Jeffrey suffered two bouts of Pneumocystis pneumonia, and on the second bout, sadly, he didn't make it. In many ways, I think he was tired of the struggle. We were all exhausted from 15 years of great anxiety and isolation.

Fred and I had to bury all of our fears and anxieties with him. We knew we had to honor his and our hopes and dreams, and try to figure out what went wrong with Jeffrey. Science hadn't caught up to our son, but we had to make it better for other families.

"While it may be somewhat of a glacial process, the work they (Vicki and Fred Modell) do has brought this into a more global awareness."

-David Greenbaum, President of Vornado Realty Trust & Jeffrey Modell Foundation Board Member

How did the creation of the Jeffrey Modell Foundation come about?

Vicki: There was no support network for us when we were searching for a cure for Jeffrey. We never met another family going through what

we were experiencing. Jeffrey never met another child with PI. We thought we were alone.

When we learned that half a million or more people in the U.S. were diagnosed with an identified PI, and another half a million or more were estimated to have it as well but were undiagnosed, we knew we had to do something.

"They have built the first immunology building ever created specifically for immunologists in this country. The Jeffrey Modell Immunology Center is on the main quad of the Harvard Medical School Campus. It was dedicated in November, 2007, at Harvard."

-Lisa Wexler, The Lisa Wexler Show & Jeffrey Modell Foundation Board Member

We established a research fund to see if we could reach a greater understanding of the disease that took Jeffrey's life. After Jeffrey passed away, many people wrote condolence notes that we kept in a big box. We started with these names and raised enough funds initially to support two Jeffrey Modell Research Fellows studying the B-cell defect that took Jeffrey's life. The fellowships were awarded to Mount Sinai Medical Center in New York City. A hotline was set up, and in only a few weeks, the phone was ringing off the hook: parents of children who were suffering from PI were coming out of the woodwork. They had many questions and were eager for information and guidance.

We established the Jeffrey Modell Foundation with five specific objectives: to conduct clinical and basic research on PI; to educate primary care physicians about PI symptoms and treatments; to provide patients and their families with information and supportive communities; to advocate for greater support at the government level; and to raise public awareness about these diseases. We developed a board, and have made great progress over the past 23 years.

Do you feel the awareness is at the level it should be today?

Vicki: We have made significant inroads, but there is still much to be done. One in every 500 people has a form of PI and doesn't know it – they just have repeated, recurring, and chronic infections without a clear diagnosis. These deficiencies

can range in severity from the case of the “boy in the bubble” – which is called Severe Combined Immunodeficiency (SCID) – where there is no immune system, to the middle range, which is where Jeffrey was, to milder cases where patients suffer from frequent pulmonary and sinus infections. These sinus infections are difficult to treat, but are more annoying than they are deadly.

How challenging was it to learn how to engage in the not-for-profit space without any prior experience?

Fred: We fumbled our way through it. I have an M.B.A. and had run a successful business, but this was new terrain for me. Yet our experience with Jeffrey showed us that there was no organization or support for families dealing with this disease. Furthermore, there were no symposia where doctors got together to exchange their latest findings, so a lot of the research was left disconnected. There was also minimal attention being paid to genetic immunodeficiencies in Washington. We knew we had to do something.

In the early '90s, we learned that acquired immune deficiency syndrome (AIDS) had \$1.4 billion in research allocated to it, while genetic or inherited immune deficiency was funded at just under \$3 million.

Now Vicki testifies before the House Appropriations Subcommittee every year. She opens her comments by saying, “Mr. Chairman, I am here not for a handout; I am here for a hand – just help us.”

Each year, we continue to build our relationships with Congress, the Centers for Disease Control (CDC), and the National Institutes of Health (NIH). As our foundation developed, many important real estate and Wall Street executives offered their help as well. It became a New York-based organization with some of the smartest people I've ever met, and we developed a wonderful and engaged board.

We also created a four-day meeting of PI experts from around the world that takes place every two years in collaboration with the International Union of Immunological Societies (IUIS). We have worked with the World Health Organization and many physicians to make this successful.

“To know the Modells is to feel privileged that they're in your life.”

-Lisa Wexler, The Lisa Wexler Show & Jeffrey Modell Foundation Board Member

Finally, we organize frequent family days for PI patients, where kids, their parents, and their doctors, get together for an event such as a baseball game, a visit to a museum, or an aquarium adventure. These take place across the country and all around the world.

Vicki: We have also encouraged a lot of the best and brightest medical students and fellows to pursue immunology studies, because we have funded so many programs around the world.

Has testing evolved to where now there can be early detection?

Vicki: Yes, early detection can certainly be achieved using the systems that we have helped develop. The first of these is newborn screening tests for SCID, which can be added to the heel stick that is used to test all babies now. Because of our advocacy, Wisconsin and Massachusetts

have added this newborn screening test for every newborn baby and we've had a few really major successes. Babies whose lives would have been lost within the first few months of life can now be cured with a bone marrow transplant in the first months of life.

Fred: The banner headline is: “Earliest possible diagnosis for your newborn or child.” If you can get it done at age one month or even six months, instead of nine years, that child is going to have a much better life.

Is it difficult to structure your platform around the world?

Fred: We have been very warmly received by our international partners. We are essentially replicating programs in New York, Boston, and Seattle and bringing them to Beijing, Brazil, Morocco, and areas throughout the world. We now have 350 expert physicians in our network, working at 138 academic/teaching hospitals – including 24 of the 30 best pediatric hospitals in the U.S. – serving 139 cities in 46 countries and spanning six continents – it's truly a global network.

Vicki: It has been wonderful to see partners in so many countries with different cultures coming together to address PI. They want us to help them establish diagnostic and research centers. The Jeffrey Modell name has become like a designer label that they all want.

Fred: Two or three years after Jeffrey's death, we had a hard time saying his name. Today, people around the world are asking for Jeffrey Modell Centers, and we're delighted. Globally, there are 60 funded centers bearing Jeffrey's name.

What's next on the agenda for the foundation?

Fred: There are three things we are committed to accomplishing. The first, as Vicki mentioned, is newborn screening. The technology has been developed to the point where we can screen newborns for SCID with a success rate of better than 99 percent. Using these results, we can cure a devastating life-threatening disease with a success rate of better than 95 percent. Without this screen, virtually all untreated babies with SCID will die within the first year of life.

Not only can we cure those babies, but we can do it economically. The test costs under \$5 per baby, but money should never be a limiting factor – we will always raise the funds to help the state public health laboratories initiate these programs through the CDC, the NIH, or the Jeffrey Modell Foundation. We must add screening for SCID to the current test panel – it is quite simply a pediatric emergency. Right now, the heel stick tests for a great number of different diseases, and we want to add just one more.

Every year, we host a big gala in New York with 600 to 1,000 people where we honor the Jeffrey Modell Foundation's “Man of the Year.” This past April, we introduced our “Man of the Year,” Dawson, who is the healthy 10-month-old son of a family in Wisconsin and the first baby in the world to have been cured of SCID through screening and bone marrow transplantation. Dawson received a standing ovation.

The second item on our agenda is something called SPIRIT (Software for Primary Immunodeficiency Recognition, Intervention, and Tracking), which we developed for third-

party payers in the health care system. SPIRIT matches patient ICD-9 codes with the 10 Warning Signs of PI, and the software generates high-, moderate-, and low-risk patients with a potential PI. Then the insurance company will notify the doctor and recommend a simple test for Primary Immunodeficiency disease. This is an effective way to diagnose people with chronic recurring illnesses who keep going in and out of the system. There is no commercial interest, no license, and no royalties – we are not looking to profit from this program. We are literally giving it away to third-party providers and asking them to use it.

“What they do is take this tunnel vision that we all bring to our lives every day and make us look afar and make us recognize that there is this extraordinary peripheral vision that we can all have in terms of doing some greater things for all of us.”

-David Greenbaum, President of Vornado Realty Trust & Jeffrey Modell Foundation Board Member

The third goal is to conduct the first-ever global symposium on PI, for June 2011. The symposium will take place in New York and will host PI experts from all of the 46 countries in which we're active, and it will also be live-streamed electronically across the globe. This will mark the 25th anniversary of Jeffrey's death, and it will be a celebration of all of the work that has been accomplished in his memory.

For those who want to get involved, is it as simple as contacting you?

Fred: There are so many ways for people to get involved, and we invite everyone to learn more about what we do and how they can help. Our Web site has information on our activities and how people can participate. It's gratifying working together to change the lives of children and families around the world.

Vicki: We are so thankful for all the help that we have received over the past 23 years. About five years ago, the CDC gave us an annual contract to do public service ads with them, and we've had over \$115 million in donated media, including television, radio, and magazines, as well as in airports and shopping malls.

Currently, we are trying to focus on Hispanic and African American outreach because those populations are grossly undiagnosed. We still have more work to do to raise awareness. But also, we ask that parents do the research and learn everything they can to keep their children healthy and happy.

Do you two ever take the time to reflect on the impact you've had, or is it always looking ahead?

Vicki: We are always looking forward, but we appreciate moments like the one when we found out that Dawson was completely cured of SCID.

Fred: The night Dawson was honored as the Jeffrey Modell Foundation's Man of the Year, we looked straight up and said, “How about this one Jeffrey?” ●