A Community Effort

An Interview with Vicki and Fred Modell, Jeffrey Modell Foundation

Fred and Vicki Modell

Jeffrey Modell

FOUNDATION BRIEF *Jeffrey Modell Foundation (JMF) (info4pi.org) 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, speaking nationwide and before the E.U. Parliament. 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, Middle East, Asia and Africa have found comfort in the expert care they receive at these facilities, as well as through JMF KIDS Days, workshops, website and social media.

Will you discuss the creation of the Jeffrey Modell Foundation and how the Foundation has evolved?

Vicki: Our son, Jeffrey, passed away when he was 15. During his lifetime, Jeffrey would always say to us, "Please, mom, dad, do something. You're smart, you went to college. Please do something." With his doctors, he would say the same thing, "Come on. You're so smart. You went to medical school. There must be some way that you can help me."

Obviously, it was extremely frustrating and extremely sad for both his doctors and for us to hear him plead like that to find some way to keep him healthy. After Jeffrey passed away, we remembered that plea of "do something" and Fred and I decided we had to spend the rest of our lives trying to figure out what went wrong with Jeffrey. We knew he had a B-cell deficiency, but we wanted to define exactly what that was and help prevent a sad and isolating event like that for another family.

Our vision was to raise a sufficient amount of money to support a Fellow or two to study this at Mount Sinai Medical Center, where he was treated. These Fellows would study B-cells and try to make a difference in the lives of people who have B-cell deficiencies. We were very fortunate to be able to raise substantial amounts of money, so one Fellow became two and Mount Sinai was joined by Boston Children's Hospital, Seattle Children's Hospital, and Children's Hospital of Philadelphia.

This kept multiplying throughout the world and we now have about 800 physicians in our network that are working at about 400 research and medical institutions. We're in 300 cities and 86 countries and it's growing every year. We're on every continent except for Antarctica. The B-cell research gave rise to T-cells and all the other cells that we have now discovered keep our immune system working properly.

Our vision has grown over the years. We expanded our mission to try to save lives for these children worldwide.

How critical is it for the network to share data and research?

Vicki: We call this our global village, because it is a rather small community of immunologists that make up the primary immunodeficiency community and they are so willing to share with each other. Best practices have now been shared around the world including parts of Africa and parts of Asia instead of just within the United States or Europe.

We've organized and hosted many medical meetings where we invite the best of the best to share their knowledge with other immunologists. We still have a ways to go in parts of the world where resources are limited, but it's getting better and better every day.

Have you received government support for these efforts?

Vicki: The government has been very good to the Jeffrey Modell Foundation. We have been given the opportunity to testify numerous times. We are the beneficiaries of very sizeable grants, and the grants are specifically for public awareness and physician education. We know that this can really never stop because there will always be more doctors we need to educate and new children born each day who may be faced with this type of illness.

Will you discuss the advances being made in this area?

Fred: There are now over 400 genetic defects that have been identified, but when Jeffrey was being diagnosed and treated, there was a lot of shrugging of shoulders and doctors saying, "We're not sure what's going on here." There were only 70 defects identified at that time. Over the years, because of what we've been doing and the education and the publishing and the symposia, more and more defects have been identified. It's a very different picture than it was in the 1970s.

Vicki: We've now developed a program for gene sequencing. Physicians and immunologists may have patients who do not have a specific diagnosis. They know it's an immune deficiency, but they don't know which one it is. We are providing a free program for genetic sequencing worldwide. We're going to 380 centers where they can take their most complex, complicated patients and we will get them sequenced.

It is being offered to them for free. The shipping, the kits and final diagnosis. Everything is being paid for by the Jeffrey Modell Foundation, because it will definitely save thousands of lives. We've learned a lot from this about what these defects are and what causes them and how we turn them off.

This is a really important program and we're very excited about our newest venture.

This effort came out of a tragic situation in your lives and you have been able to touch the lives of so many through the Foundation. Are you able to appreciate what you have built in Jeffrey's name?

Vicki: That's a beautiful question and an emotional one. I don't know that we've taken enough personal time to think about that because we're so anxious to find the next Jeffrey and to make sure that we can save that child's life. We know we've done some good but it always feels like there's so much more to do. As I said before, there is a baby being born every second somewhere in this world who might need us.

Fred: Vicki gets wonderful e-mails, letters and phone calls from people in the U.S. and around the world who say, "We've found out about the Jeffrey Modell Foundation and because of it, we've found out what was wrong with our child. My child is doing well." That's such a fulfilling and gratifying piece. ●