

Profile: Barb Ballard



When Barb Ballard's son was born with SCID, she joined the fight to increase testing for newborns, and she has become a strong advocate for SCID families.

WHEN BARB Ballard gave birth to her son Ray in 1994, doctors provided him with routine newborn screening, which came back normal, but the good news was short-lived. Ten months later, Ray lay in the pediatric intensive care unit on a ventilator struggling with pneumocystis pneumonia (PCP), a serious fungal infection that causes fluid build-up in the lungs. Doctors diagnosed Ray with X-linked severe combined immunodeficiency (SCID), a life-threatening primary immunodeficiency (PI) that results in little to no immune function. This experience led Barb to become an advocate for SCID newborn screening and families affected by SCID. Today, she is the director of SCID Angels for Life, a nonprofit dedicated to the empowerment of families affected by SCID.

By Trudie Mitschang

Trudie: Can you recall what it was like when you first received Ray's diagnosis?

Barb: I can remember asking when he was diagnosed with SCID why his newborn screening test hadn't detected it. I naively assumed anything this serious would be screened for by the test.

Trudie: Can you describe Ray's health journey growing up?

Barb: Our experience was medically complicated, and Ray battled poor health throughout his life. He underwent three bone marrow transplants with me as his donor, and he experienced severe graft versus host disease, which damaged his gastrointestinal tract. He received nutrition through a gastrostomy tube and intravenously, and he required immune globulin therapy. Antibiotics, which ultimately saved Ray's life, also left him hearing-impaired.

Trudie: Tell us about your introduction to advocacy work.

Barb: SCID advocacy became a personal passion project. I was able to start the first listserv for parents of children with SCID, and joined the Immune Deficiency Foundation (IDF) Board on which I served for 18 years. As part of my efforts, I developed the SCID Initiative program, and I advocated for SCID to be included on the national newborn screening panel at the federal Advisory Committee on Heritable Disorders in Newborns and Children in 2006. It took several years and many more meetings before the committee finally made the recommendation for SCID to be on the national Recommended Uniform Screening Panel (RUSD). However, that recommendation only meant states should consider the inclusion of SCID.

States were not bound by law to include it.

Trudie: What type of advocacy did you perform at the state level?

Barb: That's when the real battle began because advocacy had to be conducted in every state one state at a time. State newborn screening committees and legislatures were much more receptive to the pleas of parents from their own state rather than a representative from a national group, so we had to do a lot of work with local parent groups.

Trudie: When did you finally see a significant breakthrough?

Barb: By 2018, all 50 states included SCID on newborn screening panels, thanks to work by IDF, SCID Angels for Life, the Jeffrey Modell Foundation and, of course, individual families. SCID became the poster child for a new addition to the RUSD, as it was the first test to be added in a number of years. This was good and bad because, as advocates, we had no real model to follow. We gave ourselves a crash course on how and why a disease is considered for addition to the panel, and we just learned as we went along. Today, SCID newborn screening is the legacy of all SCID children.

Trudie: While you were advocating for kids like Ray, how was he coping?

Barb: Ray was a very active young man who didn't let his physical limitations hold him back. He earned a black belt in Tae Kwon Do, lettered three years in a row on the high school rifle team and volunteered with the Lions Club, the Make-A-Wish Foundation, IDF and the hearing-impaired community. His determination over his lifelong challenges became an inspiration to many people.

He always shined. Ray embraced fun, and he had a unique ability to empathize with others, putting their concerns over his own. He was a superhero to many people. Ray passed away in early 2019 after his immune system declined again, but his legacy lives on.

Trudie: Tell us about your role with SCID Angels for Life.

Barb: I serve as director of SCID Angels for Life, working closely with its founder and president, Heather Smith, and the mother of two sons diagnosed with X-linked SCID. The mission of SCID Angels is to increase awareness about SCID, provide a safe environment for families to connect, grant scholarships to those affected by SCID and provide research grants for SCID diagnosis and treatment. In my experience, parents find particular comfort in getting to know each other through our SCID Angles Facebook group. Many share similar experiences and provide each other with support and information.

Trudie: What are some of the hurdles you are facing as an organization?

Barb: One thing we've found is that local states and communities vary greatly in the depth of information they provide to parents and the quality of that information when presenting a positive newborn screen result. We've seen some parents who have been left feeling that this is no big deal, while others have been left with the impression that their child can never survive. There needs to be a way to convince more hospitals, communities and states to utilize the quality information available. SCID Angels has worked extensively with IDF on the SCID Compass project, but when presented with a positive newborn screen, many parents are never given this information or directed where to find it.

Trudie: How does SCID Angels

support families?

Barb: Those lucky enough to find SCID Angels have been ever so grateful to be part of a community that stands beside them, gives them hope and helps them navigate a new and scary medical world.

Trudie: Has the screening for newborns improved access to care?

Barb: Even now that we have newborn screening and the kids are generally able to go into treatment healthy, there are still a lot of complications with this disease. It's not a quick one-and-done and move-on-with-the-rest-of-your-life situation. We are still learning a lot about this disease. That's why there are so many clinical research trials needed to keep abreast of what is happening — what the disease and its treatment are causing, and what's incidental to the fact that these are medically complicated children.

Trudie: Is SCID Angels involved with research initiatives?

Barb: SCID Angels works closely with researchers, acting as a conduit for the needs of the SCID community. We inform researchers about commonalities across SCID families such as reverse isolation protocols and overlapping health issues with the different types of SCID. Every child's journey helps inform research. One of the things we've learned is long-term follow up is very important. Researchers have discovered how important it is to follow our children as they grow into adulthood, becoming old enough to have their own families and moving forward in life.

Trudie: What have you learned as a part of your own journey?

Barb: As a parent of a SCID child, I deal with so much that often I tell a physician only about the biggest problem that week or that day. There's too much to go over. And consequently, physicians

don't often realize the full spectrum of challenges these families face. But if we learn to speak up and share our stories, perhaps they'll begin to recognize similarities in more families. The more information shared, the more we are able to empower each other. As Heather and I continue to say: "Knowledge is power!"

Trudie: How did you balance caring for Ray and patient advocacy work in the early days?

Barb: The early days of my advocacy work were completely volunteer, so I could allow myself to focus first and foremost on Ray and his needs. But, my advocacy work was important to me and, consequently, much of my free time was dedicated to that. I realize, too, that during that early period, Ray was still in very strict reverse isolation and wasn't allowed to be around any other children and very few adults. So, I was isolated at home with him, and my outreach to other SCID moms helped me find a community, as well as a way to help them.

Trudie: What advice do you have for other parents of PI children?

Barb: Find and embrace your community. No matter where you are in your journey with this disease, you have much to share, and you'll find a lot of comfort and relief knowing that you're not the only one facing these challenges. While it can be difficult at times to be part of a community in which you are given a glimpse into the lives of other very fragile children, the depth of understanding and acceptance of other parents who understand your own fears and concerns is a priceless gift. 



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