

The Conference was also an eye-opening experience for Linda.

“It was nice for Carly to see other children going through the same thing,” explained Linda. “We met so many people who were incredibly supportive, friendly and welcoming. We owe Dr. Torok and the Foundation a big thank you.”



**“Our hope is that more families can experience the power of the conference and the support of others living with scleroderma.”**

The conference is the largest patient-focused scleroderma meeting in the world. It brings together leading researchers and other healthcare professionals and those living with scleroderma for an unparalleled education experience.

**Please make a generous donation to the Annual Fund today and help us meet our goal to provide at least 50 scholarships to those who would not otherwise be able to attend to this year’s conference in New Orleans, LA.**

For more information on the Conference, please visit [www.scleroderma.org/Conference](http://www.scleroderma.org/Conference)

## How Your Contribution Helps

**Support.** The Foundation is dedicated to providing a place for those whose lives have been touched by scleroderma where they can connect with others through an active on-line community, a toll free Helpline staffed with knowledgeable and compassionate people, and by activities, events, fundraising initiatives, and community awareness programs that happen throughout the country via the Foundation’s network of chapters and support groups.

**Education.** Information on treatments and research initiatives, conferences, brochures, and news publications, particularly the Foundation’s quarterly magazine, the Scleroderma Voice, are just some of the ways that the Foundation educates patients, families, the medical community, and the general public about scleroderma. Public relations and advocacy programs serve to inform the public and government leaders. These efforts are multiplied many times over by the programs and services of chapters and support groups nationwide.

**Research.** The Foundation’s peer reviewed Research Program makes available an average of \$1 million annually in grants to new and established investigators. Grants from the Foundation have served as “seed” money for many research initiatives that have grown into large-scale studies with funding from the National Institutes of Health. From these, new insights are made that may lead to the development of therapies and, hopefully A CURE.

Meet Newly Diagnosed Carly Bankovich





Carly and her mother Linda at the Conference.

## Carly and Linda Bankovich attended the 2015 National Patient Education Conference thanks to your generosity.

Two years ago, 12-year-old Carly Bankovich was in the middle of her basketball game and knew something didn't feel right. She just didn't know what.

"My hands were not moving like they should have been," remembers Carly. "The skin on my arms was hard and my hands were really stiff."

Unlike many scleroderma patients, Carly's diagnosis was a quick one.

"My primary doctor said that in his thirty years of practicing, he had never seen anything like this before," said Carly. "So he immediately referred me to Children's Hospital in Pittsburgh – specifically to Pediatric Scleroderma Clinic director Dr. Kathryn Torok. Dr. Torok knew right away what I was dealing with. I had never heard of scleroderma before. I was so scared."

Dr. Torok introduced the Bankovich Family to the Scleroderma Foundation where



she knew they would be in good hands for additional support and information. "I've been blessed to have such a great doctor and the people at the Foundation," Carly said. "It must be so hard for someone who doesn't have supportive people around them."

Dr. Torok has played a critical role in Carly's care and Carly's father, Joe, wanted to recognize her for her efforts. His company, Penn Metal Stamping, organized monthly fundraisers and presented Dr. Torok with a check to the Scleroderma Center and a commemorative plaque.

Soon after her diagnosis, a fellow employee at Joe's company mentioned that she had a granddaughter Carly's age who had also recently been diagnosed with scleroderma.

"We couldn't believe what a small world it was for such a rare disease," Carly's mother Linda said. "The girls got together soon after and were a great support to one another."

"One of the things they talked about was that Carly's new 'scleroderma friend' was going to the 2015 National Patient Education Conference in Nashville, Tenn.," Linda continued. "Dr. Torok had talked about the conference to us just a few weeks before."



attending I was able to explain scleroderma so much better to my friends and teachers. I didn't even know there were different kinds of scleroderma before that. It was sad to see other patients dealing with worse symptoms than me but it made me appreciative of how far I've come since starting treatment. I also couldn't believe how many miles some patients had to travel to see special doctors. It really was an awesome experience."

"We were excited that there was a juvenile program at the Conference designed for families just like ours," Linda mentioned. "However, we were not in a position to attend given our mounting medical bills. But Dr. Torok told us about the possibility of scholarships. We applied and were so grateful that Carly received one."

"I was excited to attend the Conference," beamed Carly. "I met so many other kids just like me. Just knowing that I wasn't the only one in the world dealing with this was a relief. The conference was educational and so informative. After

