

KGS2!

Kids Get Scleroderma Too!



The planning began with an idea – how can we partner with local physicians to hold an event forum specifically focused on juvenile scleroderma? Our work took off soon enough as we started to build a relationship between

Tri-State and three pediatric rheumatologists who had submitted and were given a grant from the Scleroderma Foundation to do a research project focused on children: Suzanne Li, MD, PhD of Meridian Health, Hackensack, NJ; Kathryn Torok, MD of Children's Hospital of Pittsburgh, PA and Anne Stevens, MD, PhD of Seattle Children's Hospital, WA.

Planning for KGS2! (Kids Get Scleroderma Too!) got started in January 2016. The plan involved organizing a program that would offer specific information to a variety of people based on age. Dr. Li kept our momentum going with meetings, numerous emails and phone calls. She also recruited a variety of people from Hackensack to help direct and guide us as well as host the event at the John Theurer Cancer Center, Hackensack UMC. Everyone got on board, spreading the message to parents and families - that this free event was a unique opportunity for them to learn, network and create bonds that could support them long after the conference ended.

To kick off this special event, we planned an awesome Halloween Costume Party at the Hilton Hasbrouck Heights. From the Skyball Room attendees enjoyed an awesome view of the NYC skyline. The party featured a DJ who rocked us through the night, a photobooth that was very popular especially with our young

attendees; awesome food and plenty of treats for all! Mary Beth Bobik-Kadylak, SF Tri-State's director of patient education and support played hostess that night and felt it was key to the event's success – "it was a great way to break the ice, dance and be silly while getting to know the kids and their families a bit better."

The next morning, the conference was held at Hackensack UMC and included a keynote speaker, break-out sessions based on group needs and wrapped up with door prizes, and ice cream sundae bar and the exchange of information between parents to keep the momentum going long after the day closed. The conference itself was attended by one hundred and twenty-five persons including physicians from five states and families from ten states - some from as far away as Washington and California! The conference was divided into sections for siblings, kids 5-12, teens 13-17 and adults. We hoped to provide specific programs that were meaningful to all attendees based on age - and it worked very well!

Special thanks to our sponsors who were so important to our success including: Actelion, Bayer, Reata, FibroCell, A Lasting Mark, Mr. Speaker, DEG Sound, the Marion Brucker Legacy Fund and Hackensack Meridian Health!



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