



Barth Syndrome
Foundation

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Saving lives through education, advances in treatment, and finding a cure for Barth syndrome.

2018 BSF Conference: Share in the Breakthroughs of Tomorrow, Today

By Marilyn Toth, Wife of Barth Syndrome Foundation Science Director



(L-R) Jeff, Marilyn & Matt

My first BSF conference was in 2008 with my husband, Matt, who is the Science Director of BSF, and our son, Jeff, who was 16 years old at the time. I was finally able to place faces with the names I had heard Matt speak of so often. I not only was able to meet the affected boys and their families but also the scientists and doctors who were working towards a treatment and who cared for many of the boys. I was struck by the strong sense of community and came to realize how different this conference was going to be.

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"...The biennial meetings of which I was privileged to attend the first three have become very popular, attracting many affected families, medical specialists and scientists, all interested in Barth syndrome."

~ Peter G. Barth, Emeritus professor of congenital diseases of the nervous system, Emma Children's Hospital, University of Amsterdam, the Netherlands

Jeff and I attended a variety of the Science and Medicine talks which we found to be very interesting. Since I have a nursing background, it was especially informative to speak personally with some of these scientists and learn more about their work. It was impressive to see all the different areas of research presented according to the symptoms which impact Barth syndrome individuals. The clinics held at the conferences are a way to gather information that is useful and critical to doctors, scientists, and families. My son, Jeff, although not affected by Barth syndrome, has participated in some of the clinic studies to help better understand this disease.

As each day of the conference progressed, Jeff and I were able to chat with some of the families at mealtimes. The social, which is held on the last evening of the conference, was a fun way to get to know and dance with the BSF community members. It was heartening to see the boys having a great time. BSF is really like one big family with the same hopes and dreams for a better tomorrow. On the last afternoon of the conference, I remember feeling so touched by the slideshow presentation of all the BSF families. It was an enjoyable conclusion to a special conference that has the potential to enrich every participant's life.

Since 2008, Jeff and I have attended more BSF conferences and enjoyed meeting old friends and making new ones. Each time, I am overwhelmed with emotion as I participate in the conference. It amazes me to see how everyone involved works tirelessly in their diverse roles to make these conferences a great success each time. As for the boys and their families, I have the greatest regard for their perseverance and their abilities to overcome the obstacles they face daily. These families are my true superheroes.

At the conference families are able to share their personal stories with one another making it an event that is valuable and encouraging. I believe that we gain so much from meeting individuals who have been through a certain experience. The knowledge received from them is priceless. It also brings some level of comfort to speak with others who have had a similar experience.

As the 2018 BSF conference approaches, why not come and share in the knowledge, experiences, and love that this unique community possesses.



Conference attendees at BSF's 2016 conference (Photos courtesy of Amanda Clark ²⁰¹⁶)