Quote of the Day:

"I am so grateful for all that BSF has become, for all the Foundation does, but for me, one of the most breathtaking things about BSF is that we are no longer alone. We couldn't make progress alone. We very much need each other. Just as when we started the Foundation, we don't know what discoveries lie ahead for our sons. But we do know that we can make so much more progress together." ~ *Sue, Mother of Diagnosed Son, Nebraska*

Featured Story: A Personal Message from Sue

We're No Longer Alone

(L-R) Anna, Sue, and Shelley leading a group discussion at the fist-ever Barth Family Gathering

In 1998, Anna, Shelley and I "met" and started communicating via the internet. We each had a son with Barth syndrome. I remember that we emailed daily—we were so thrilled to find another mother going through many of the same ups and downs of living with a child affected by Barth syndrome.

We knew there were other families who were affected by Barth syndrome and we felt a sense of urgency to find them. And so with the help and encouragement of Dr. Kelley, we started planning the Barth Syndrome Family Network gathering, which took place in Baltimore, Maryland in June of 2000.

It was an indescribable weekend. First, Anna, Shelley and I met for the first time face to face. Second, we met all the courageous families who travelled from all over the world to find help, hope, and other families struggling with the same thing they were – Barth syndrome.

Families came for this one weekend from South Africa, Portugal, Scotland, Canada, Australia, and the US. Dr. Barth and several of his colleagues, including Dr. Ron Wanders, came from Amsterdam. And, Dr. Kelley was right there with us, helping us plan the meetings.

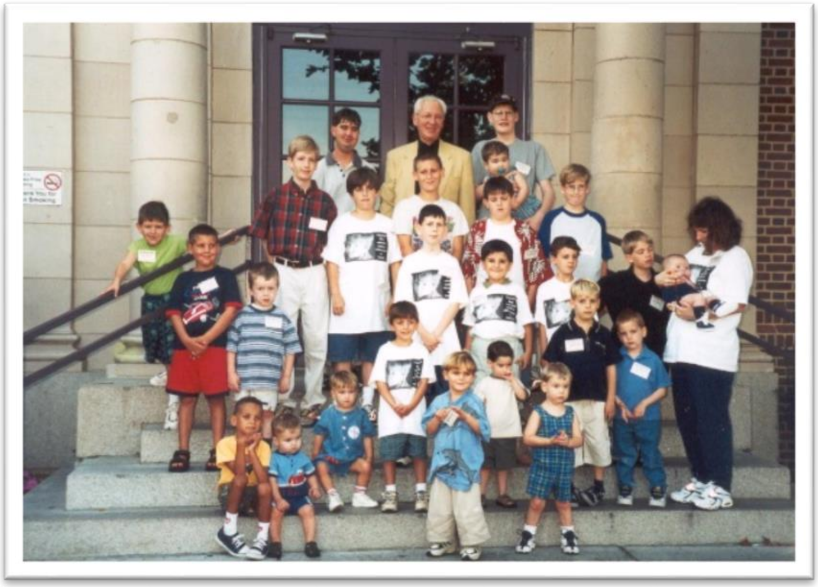
(L-R) Sue, John, & Jessica

I remember looking around at the other parents, boys, siblings, grandparents, and aunts and uncles who attended that weekend and realizing we were no longer alone. For our family this was an extraordinarily development. Our son, John, now 29 years old, was 11 years old when this disorder was named Barth syndrome. Until that time his diagnosis was “X-Linked Cardiomyopathy.” And we knew of no one who was going through the same thing.

At the end of this weekend when the families gathered together for the last time, we voted unanimously to form the Barth Syndrome Foundation. We had no idea what we would accomplish in the next 11 years.

But we knew we had each other, we knew there were more families to find, we knew there were answers to be discovered, and we knew we would be much stronger together.

I am so grateful for all that BSF has become, for all the Foundation does, but for me, one of the most breath-taking things about BSF is that we are no longer alone. We couldn’t make progress alone. We very much need each other. Just as when we started the Foundation, we don’t know what discoveries lie ahead for our sons. But we do know that we can make so much more progress together.



Dr. Peter Barth (center) with many of the boys and young men who attended the first-ever Barth Syndrome Family Gathering in Baltimore, MD in 2000.