
2018
ANNUAL REPORT
Barth Syndrome
Foundation

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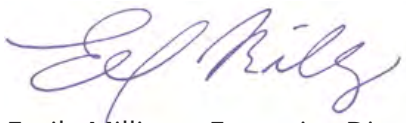
2018 was a pivotal year for Barth Syndrome Foundation (BSF)!

- BSF engaged in high-level discussions with drug development agencies such as FDA and began to execute an advocacy agenda with regulators. Families provided a collective voice at the Patient-Focused Drug Development Meeting that was witnessed by individuals from the FDA, research, and industry.
- The first clinical trial ever for people with Barth syndrome was fully enrolled and completed, marking a milestone in rare disease drug development.
- Our global community came together at the largest Barth Syndrome Scientific, Medical, and Family Conference ever attended, representing over 12 countries and 228 family members.
- BSF welcomed me with open arms and eager hearts into the #BarthFamily.

BSF is responsive to family needs and tireless and innovative in our approach to research. Multiple publications and research collaborations have been made possible, in concert with our international affiliates, by BSF's financial support, and our involvement with Barth syndrome leaders around the world. This is incredibly exciting given that today BSF is emerging as a valuable partner at every stage of research and development, from basic science to clinical trials and beyond.

But what inspires me most is the BSF family. The families who live with Barth syndrome and the clinicians, researchers, friends, neighbors, teachers, and supporters who care about them are compassionate, patient, and tenacious. They are tender and supportive in crisis yet fierce in the face of adversity. When I look at them, I see where the mission of BSF was born and feel the urgency to create a world where Barth syndrome no longer causes suffering or loss of life. I ask you to join me in this pursuit and offer your help so that, together, we can bring to fruition treatments and a cure for Barth syndrome.



Emily Milligan, Executive Director

"Barth Syndrome Foundation is a true example of how groups for rare diseases should be run. The way they bring patients, families, doctors, and scientists together is unique and the amount of knowledge gathered in its mere 18 years of existence is mind-blowing."

- Peter, with BSF Executive Director Emily Milligan at BSF's International Conference in 2018. Peter lives with Barth syndrome.

About Barth Syndrome Foundation

Barth Syndrome Foundation (BSF) is the only global network of families, healthcare providers, and researchers solely driven by the mission to save lives through education, advances in treatment, and finding a cure for Barth syndrome. BSF has funded nearly $4.9M USD since 2002 and catalyzed over $21M USD in funding from other agencies to advance global scientific discoveries to end the suffering and loss of life from Barth syndrome. Additionally, BSF provides a lifeline to families and individuals living with Barth syndrome around the world, offering 24/7 individualized support, educational conferences, a robust patient registry, and collaborations with specialist healthcare providers to define standards of care, treatment, and rapid diagnosis.

What is Barth Syndrome?

Barth syndrome is a rare, life-threatening, genetic mitochondrial disorder primarily affecting boys. Affected people may suffer from heart failure, muscle weakness, and infection (caused by neutropenia). Additional characteristics of the syndrome commonly include growth delay, impaired lipid metabolism, fatigue, and cardiolipin deficiency. In some people affected by Barth syndrome, the symptoms can be very severe, sometimes resulting in heart transplant, potentially lethal infections, and even death.

1/3

Roughly a third of all individuals with Barth syndrome have been told by their doctor that they may need a new heart at some point in their life.

Fast Facts About Barth Syndrome

- Barth syndrome is caused by a chromosomal mutation in the *tafazzin* gene.
- Because the genetic defect is on the X-chromosome, Barth syndrome overwhelmingly affects boys.
- Currently, there are no approved treatments and no cure for Barth syndrome.
- Most babies with Barth syndrome experience symptoms within their first year of life.
- A simple scratch or bug bite can lead to a life-threatening infection because the individual's body has a hard time fighting infection.
- Extreme fatigue can result from activities most of us take for granted, including walking, writing, eating, and growing.
- Roughly a third of all individuals with Barth syndrome have been told by their doctor that they may need a new heart at some point in their life.

VISION

A world in which Barth syndrome no longer causes suffering or loss of life.

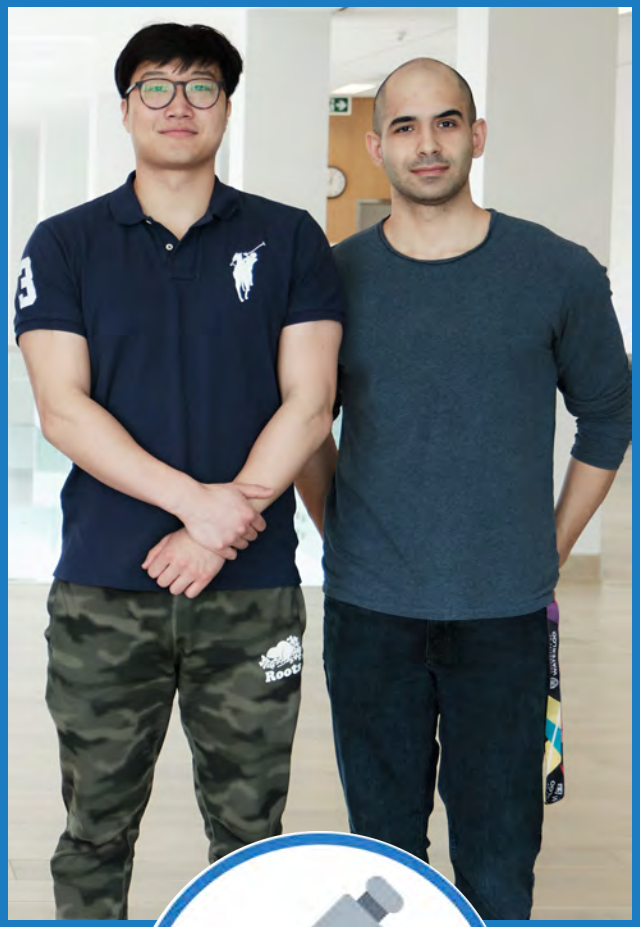
MISSION

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

VALUES

We will ensure that BSF means: Credibility, Integrity, Professionalism, and Compassion.

BSF's Program Pillars



FAMILY SERVICES

RESEARCH

ADVOCACY

Impact At A Glance

FDA meeting
BSF became the 14th organization to host an externally-led Patient-Focused Drug Development (PFDD) Meeting with the U.S. Food and Drug Administration (FDA). More than 25% of the Barth community voiced their experiences.

Successful conference
228 family members, including 50 affected people, representing 12 countries, attended the 2018 BSF Conference, the largest family gathering yet. 96 scientists and doctors attended the science/medical sessions and 5 IRB studies were conducted.

First drug trial
Stealth BioTherapeutics' TAZPOWER clinical trial found that elamipretide may offer benefit by changing the biology associated with Barth syndrome, resulting in improved quality of life for some.

Scientific breakthroughs
Christina Pacak, Barry Byrne, and a team of researchers found that gene replacement improves cardiac proteomic profiles in preclinical models, suggesting a potential clinical pathway for gene therapy in Barth syndrome.

Leading research
Our 2018 research grant recipients demonstrated innovative and scientifically rigorous approaches to addressing knowledge gaps in Gene Therapies, Modification of Cardiolipin, and Improving Mitochondrial Function.

Building on success
Due to strides being made in treatments for Barth syndrome, including the first clinical trial and the PFDD Meeting, BSF received an anonymous $1 million gift. We also had our most successful Giving Tuesday, raising more than $65,000.

BSF leadership
BSF introduced its new executive director, Emily Milligan, in May 2018. Her career has always focused on programs for children and underserved populations. Emily brings a wealth of knowledge and passion to her role with BSF.

BSF ListServ & Registry

Transforming stories into science

LISTSERV & REGISTRY

Families share their stories and experience.

OBSERVATIONS & DATA

Simple observations and data collected through the registry become research priorities.

RESEARCH ➡ THERAPIES

From bench to bedside, research drives the potential for viable treatments.

THERAPIES = IMPROVED OUTCOMES

Therapies improve quality and quantity of life for people with Barth syndrome.

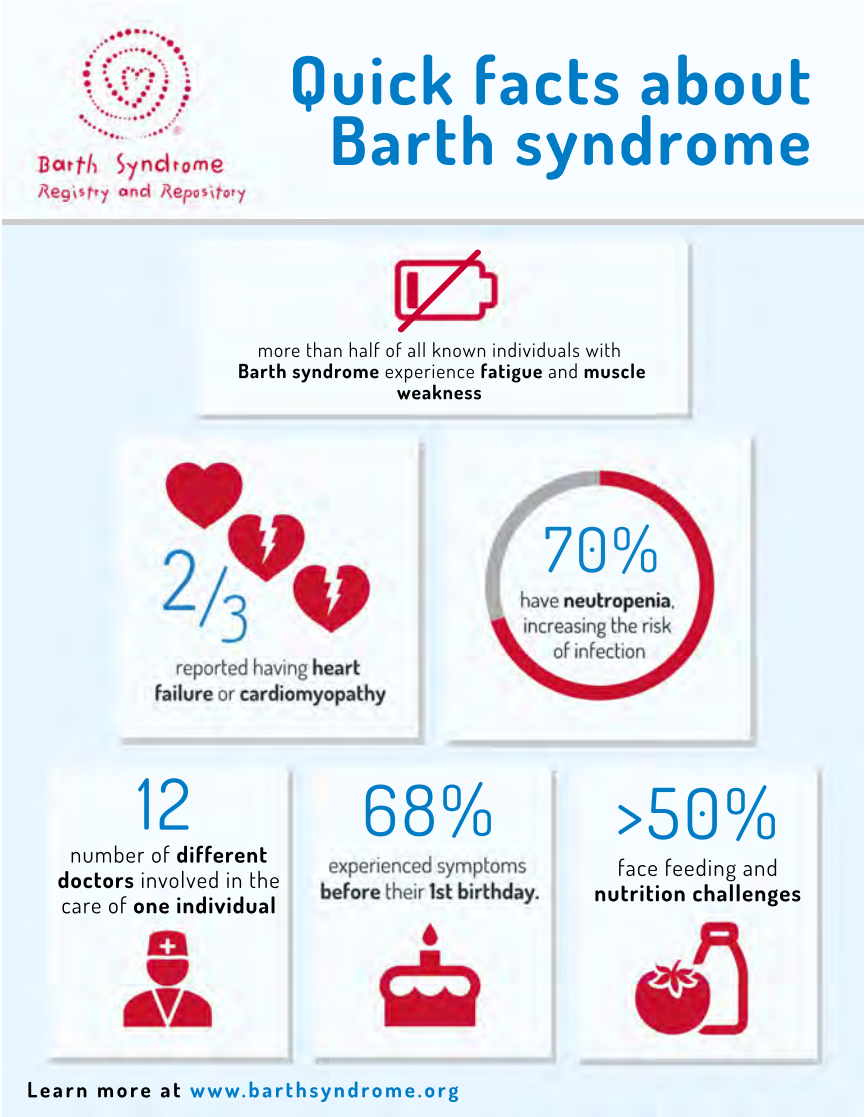
Patient Registry

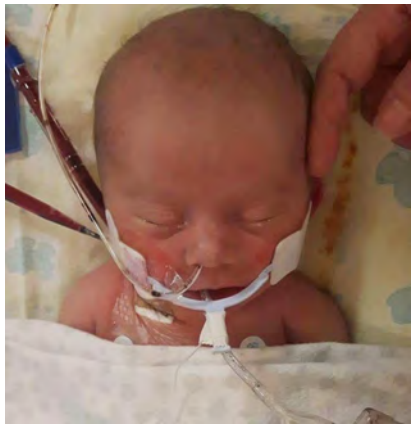
The purpose of the Barth Syndrome Registry and Repository (BRR) is to amass information and biological specimens from individuals with Barth syndrome into a single database that will be utilized by researchers to better understand Barth syndrome. The BRR has made possible academic advancements in cardiac function, heart transplants, and neutropenia. In addition to informing the natural history of disease, BSF has used findings from the registry to inform organizational research priorities.

Shelley Bowen, BSF's Director of Family Services & Advocacy, champions the registry: **"Data compiled through BSF's registry has been the driving factor behind the collective understanding of the disease, as well as a powerful source for directed research strategy and funding."**

In the coming years, the registry will serve as a critical resource in clinical trial design and execution. Notably, BSF's families and affected individuals are the unsung heroes who have made the findings and future studies possible through their ongoing contributions to the registry. Read more at **barthsyndromeregistry.org.**

Barth Syndrome Registry and Repository





Caleb

At birth, Caleb had trouble breathing and within four hours was airlifted to BC Children's Hospital. On his second day of life, he went into cardiac arrest and after 22 minutes of chest compressions was placed on life support. We were told our son was in complete heart failure and they didn't expect him to survive. On Day 13 of life support, his doctors feared he would suffer a stroke and they were going to disconnect him. They strongly encouraged us to say goodbye to our baby. Although Caleb's heart had recovered slightly, it was still so weak that he couldn't breathe on his own and he remained intubated for 93 days. We received a diagnosis of Barth syndrome on Day 21 and immediately began researching as much as possible; even Caleb's doctors had never heard of this rare disease. During Caleb's six months in the hospital he suffered from multiple infections, severe GI issues, and many near-death incidents.

Today, Caleb suffers from intermittent neutropenia. He receives injections of G-CSF to boost his white blood cells; it is extremely disheartening to have to pin our 2-year-old son down twice a week for an injection he strongly resists. Caleb also suffers from extreme low muscle tone, which affects his heart function, development, and feeding. Caleb appears to be a healthy and happy little boy. What you cannot see is his heart failure, his poor immune system, his weak muscle tone, his extreme fatigue and pain, and his frustration. Living with Barth syndrome is living with the unknown and the constant fear of what your child's life will be.

"When we got the diagnosis for Caleb, there was an overwhelming feeling of isolation. We were overwhelmed and exhausted from all the research we were trying to do. Caleb was given a diagnosis that, in a sense, is invisible to most people, and the weight of this and the uncertainty of his future stole our breath and exhausted us. And then we found Barth Syndrome Foundation. We found a community, a family that could give us resources and real-life experiences. Finding the foundation gave us comfort and hope and strength that we needed to continue on the journey alongside Caleb."

- Jasmine, mother of Caleb

Peter

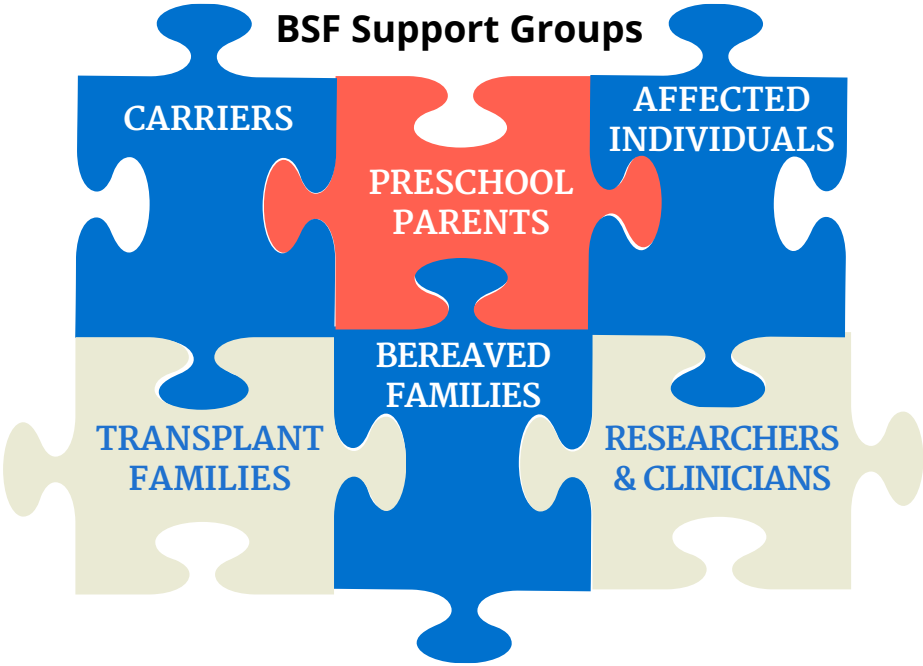
At 32 years old, Peter is one of the "elders" in the Barth syndrome community, having lived with the disease since he was diagnosed at the age of 2. Peter is a tireless advocate for himself and others and takes the opportunity to help define Barth syndrome seriously by sharing his experience and participating in research as much as possible. Despite his valiant attitude, the fatigue that Peter experiences as a result of his condition is nothing short of debilitating. Peter understands what it means to make the most of every day. "I believe it is important to make the best of every day within the best of your abilities," he says. Chronic pain and muscle weakness contribute to Peter's fatigue, sometimes making it difficult to stay positive. Hope is what keeps Peter going, even when the symptoms caused by Barth syndrome compromise his ability to stay engaged in "normal" society. "The hope for advances in research and treatment is what inspires me the most. Without that, I'm not sure what would keep me going." Many young people with Barth syndrome do not live past early childhood, making Peter's determination inspirational to BSF families around the world.

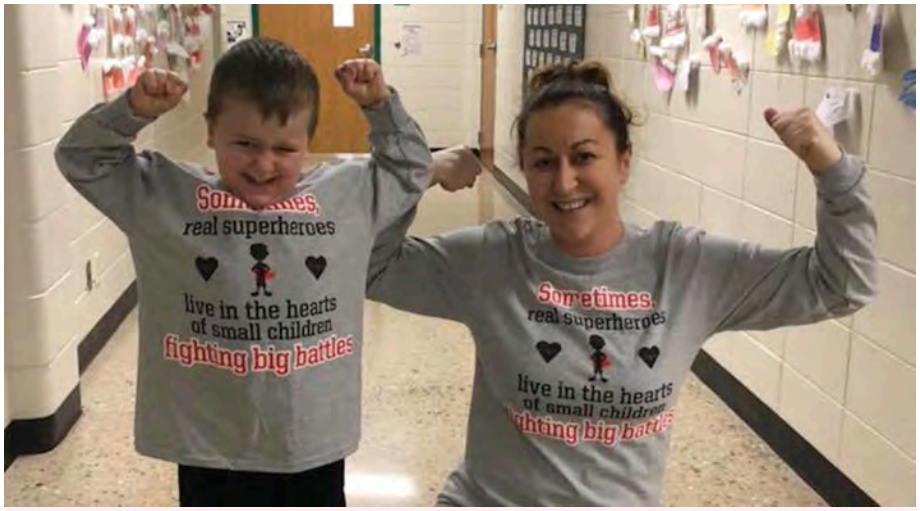
Family Lifeline

When families find Barth Syndrome Foundation, they find hope and support. BSF and the BSF Family Services' volunteers provide a caring community that offers each Barth family information, guidance, and emotional support. "You are not alone," says Shelley Bowen, BSF's Director of Family Services & Advocacy. "We are here for you."

Bowen and volunteers comprise a community of parents, grandparents, wives, sons, daughters, affected individuals, and extended families, so a family in need always can find a meaningful connection.

BSF gives families the tools and resources they need to build the confidence necessary to become informed advocates.





"Barth Syndrome Foundation has literally helped our family in so many ways, there are not enough 'thank yous' in this world to thank them enough for what they've done for my son and our family. They are always there for us in any way we need them."

- Amy, mom of Levi

Patient Voices

In July 2018, Barth Syndrome Foundation became the 14th organization of more than 7,000 rare diseases to host an externally-led Patient-Focused Drug Development (PFDD) Meeting with the U.S. Food and Drug Administration (FDA).

Kevin and Jacob speak about Barth.

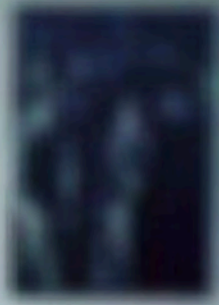
The PFDD Meeting increased awareness and educated the FDA about the challenges of living with Barth syndrome and influenced both trial design and regulatory decision-making. The half-day event focused primarily on a range of viewpoints of Barth syndrome. Panelists and speakers covered symptoms and impacts on daily life that are most important to affected individuals and their perspectives on existing and future treatments.

More than 25% of the Barth syndrome community, representing more than 12 countries, converged to voice experiences and perspectives of living with and caring for someone with Barth syndrome.

Shanon Woodward, from the FDA's Center for Drug Evaluation and Research, commented, "We are incredibly grateful for the opportunity [the Barth syndrome community] provided us in sharing their stories."

IMPACT

“I don't owe anyone an explanation for who I am. I don't do this for you, but for myself. I will never have muscles like others. I don't owe anyone an explanation but today was a new record and that's why I'm doing it, overcoming myself, not others. For the joy!!!!!!”
- Matej



2,150
Number of donors to Barth Syndrome Foundation around the world in 2018

$4.9 million
Amount BSF has invested in Barth research since 2002

2
Number of clinical trials for Barth syndrome patients

254
Number of living affected people worldwide

12
Countries represented at our PFDD Meeting in 2018

Timeline

1983
Disorder first described by Dr. Peter Barth

1996
Tafazzin gene discovered to cause Barth syndrome

2000
BSF incorporated as a 501(c)(3) organization

2001
Scientific Medical Advisory Board created at BSF

2003–2006
Yeast, Fly, and Zebra Fish models created to analyze severity of human *TAZ* mutations and to test potential treatments (*grant support from BSF*)

2006
Barth Syndrome Registry and Biorepository established

2006
Kulik et al. establish MLCL/CL bloodspot assay as diagnostic *(grant support from Barth Syndrome Trust)*

2007
100 known living people with Barth syndrome

2009

BSF develops knockdown (KD) mouse and generates critical research tool to facilitate studies of Barth syndrome

2013

Reynolds et al. suggest sensory issues related to feeding and eating *(grant support from Association Barth France)*

2014

Pu et al. iPS cell work in Barth syndrome acclaimed as **top 10 cardiovascular disease research advances of 2014** *(grant support from BSF)*

2013

Strathdee et al. develop knockout (KO) mouse for researchers to study the effects of *TAZ* deletions *(grant support from Barth Syndrome Trust)*

2016

200 known living people with Barth syndrome

2015

Taylor et al. characterize and document pain to increase healthcare provider awareness and inform pain management standards of care *(grant support from BSF)*

2017

BSF collaborates in 1st clinical trial initiates to test investigational new drug (elamipretide) in Barth syndrome

2018

BSF hosts externally-led Patient-Focused Drug Development Meeting with U.S. Food and Drug Administration (FDA), launching regulatory advocacy agenda

Scientific Breakthroughs

Barth syndrome likely underdiagnosed

Neutropenia, the loss of a certain class of white blood cells, can lead to life-threatening conditions from uncontrolled infection. A recently published study by Colin Steward, *"Neutropenia in Barth syndrome: characteristics, risks, and management,"* from data collected from the Barth Syndrome Registry over 10 years, highlights the use of granulocyte colony stimulation factor, or G-CSF (Neupogen), to help diminish the dangers from neutropenia. The study advocates that a diagnosis of Barth syndrome should be considered in any males with neutropenia who also experience other cardinal symptoms of Barth syndrome. Researchers support the use of Neupogen to help prevent serious infections that are a problem for many people with Barth syndrome, especially those who have catheters, PIC lines, pacemakers, or other devices that act as an entry point for bacteria.

AAV9 vector shows promise in mouse model

An AAV9 vector optimized for human expression with human *tafazzin* was able to reverse the cardiac and fatigue phenotypes of the knockdown mouse model with three different promoters (CMV, desmin, and native *tafazzin*). The AAV9 vector with the desmin gene promoter driving *tafazzin* expression is the favored clinical test candidate because it provided the best reversal in many of the phenotypic dysfunctional traits analyzed. These are promising results pointing to next steps to test toxicity in non-human primates before entering a clinical trial.

Enzyme replacement therapy potential opportunity

Dr. Michael Chin of Tufts Medical Center (Boston), recipient of multiple BSF research grants as well as an NIH RO1 grant, is a leader in the field of enzyme replacement therapy (ERT) as a potential mechanism for treating people with Barth syndrome. In a seminal 2018 publication entitled, "*Identification of novel mitochondrial localization signals in human Tafazzin, the cause of the inherited cardiomyopathic disorder Barth syndrome,"* Chin describes how *TAZ* peptides generated by CRISPR technology can help improve scientific understanding of how the *TAZ* gene and human TAZ protein influence communication and function within the cell and the mitochondria. People with Barth syndrome have a defect in the *tafazzin* gene, which causes subsequent deficiencies in *tafazzin* enzyme. ERT in Barth syndrome is increasingly being evaluated as a potentially viable therapy that will fix the causative biological defects resulting in Barth syndrome.

"I have worked with Barth Syndrome Foundation for more than 15 years as a physician and a researcher. They are well organized and focused on education and advancing treatment for Barth syndrome for families, scientists, physicians, and health professionals. They have a terrific record of funding research, including clinical, basic science, and translational research. They have a unique conference every 2 years that brings together families, scientists, and clinicians. The foundation … is a model foundation for rare disease advocacy."

- Carolyn Taylor, MD, MUSC

Clinical Trials

Led by Dr. Hilary Vernon at Johns Hopkins, Phase 2/3 of the **TAZPOWER** clinical trial ended in December 2018. TAZPOWER was a double-blind, placebo-controlled, randomized crossover trial. Following completion of the trial in December 2018, participants could elect to stay on the interventional drug during the open-label extension (OLE) period. Continued duration of therapy with elamipretide suggests favorable reductions in a key biomarker for Barth syndrome. This finding suggests elamipretide may offer therapeutic benefit by changing the underlying biology associated with Barth syndrome, resulting in improved quality of life for at least some individuals with Barth syndrome.

Coordinated by the NHS National Barth Syndrome Service: Barth Syndrome Clinics, the **CARDIOMAN** trial reached a milestone in 2018. Prepared to enroll the first patient in 2019, the CARDIOMAN trial will be the second clinical trial ever to test an interventional therapy in Barth syndrome. The trial is sponsored by the National Institute for Health Research (NIHR) in the UK to test bezafibrate, a lipid-lowering drug that has been safely and broadly used in Europe to treat hypercholesterolemia since approval in 1978. CARDIOMAN aims to investigate the effectiveness of bezafibrate on lipid metabolism and subsequent heart function in boys and young men with Barth syndrome.

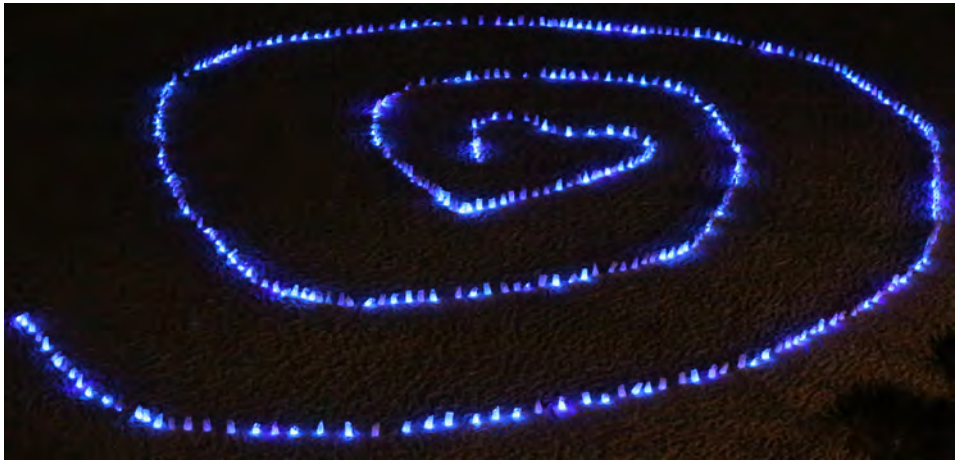
We are family

Our mission is to save lives through education, advances in treatment, and finding a cure for Barth syndrome. What our mission implicitly states is that we also believe it is important to promote a sense of community built on personal relationships. When people are in need, they call upon friends. Following the conference, a Barth family from Italy took some time to see the United States. While visiting a museum, their car was broken into and all of their son Pietro's medications were stolen. Pietro's mom called upon her Barth family to help.

Tiffini (Henry's mom) met Paola (Pietro's mom) at Riley Children's Hospital to share some surplus Neupogen she had in stock, saving the family's vacation and saving them thousands of dollars that it would have otherwise cost to fill the prescription.

2018 International Conference

The 2018 Barth Syndrome Foundation Conference drew the largest family attendance ever: 228 family members, including 50 affected people, representing 12 countries. There were also 25 posters, with one-third of them first-time attendees, and 96 doctors and scientists.



The biennial conference brings together families, scientists, and clinicians to create opportunities for studies and scientific collaborations and allows families to share their experiences.

"For 6 days I have been in back-to-back meetings surrounded by people from the Barth Syndrome Foundation community. [Then] my agenda was empty and so was the hotel. For a week I was a part of the majority where I fit in, surrounded by people who knew and understood my limitations due to Barth syndrome. When they were gone, I felt out of place and longing for more." -- *Peter, BSF 2018 Conference Attendee*

In Memory Of …

Ryan Sernel

Ryan Sernel, 12, was a parent's dream. He was a great kid who did all the right things — he was kind, polite, respectful, a model student, and just so much fun to be around. The son of Marc and Tracy Sernel lived life to the fullest, with a smile on his face and joy in his heart. Tragically and suddenly, Ryan lost his battle with Barth syndrome in March 2018.

"If there is one word that defines Ryan, it is LOVE. Love just poured out of Ryan, especially toward all of his family members that he loved so much," said Ryan's dad. "To know Ryan was to love him," his mom said. "His love, kindness, caring, and sweet nature touched so many lives. Ryan was everyone's friend. He was super smart and witty, and had an innate ability to connect with people. Words cannot express how much we love our Ry and miss him every single day. He was our family's bright light and always will be."

The Sernel family, from left: Douglas, Tracy, Catherine, Marc, and Ryan.

Ryan touched many during his 12 years on Earth, and his passing has left a huge void. "We had a real-life angel in our lives. It is now our job, all of our jobs, to be a little more like Ryan," Marc said. "Make someone feel loved. Bring smiles to others' faces. Help those in need. Show empathy and compassion. Don't take things, or yourself, too seriously. Don't dwell on your limitations, and do what you are able to the best of your ability."

Brayden

Brayden was discovered to have dilated cardiomyopathy following a week-long hospitalization when he was 16 months old. This led to his diagnosis of Barth syndrome, which is characterized by his dilated cardiomyopathy, weakness in his muscles, and a small number of white blood cells resulting in recurrent infections. All of this meant that Brayden had difficulty keeping up with other children as he grew older.

In December 2014, Brayden's health declined quickly, and he was put on the heart transplant list. After spending more than three months in the hospital's intensive care unit, Brayden received a new heart, and just a few weeks later, he was able to go home. He has since recovered well, transitioning from liquid medicine to pills and undergoing physical and occupational therapy.

But no matter how much improvement Brayden achieves, he and his family must always be on the lookout for rejection of his new heart, and deal with the other devastating effects of Barth syndrome. BSF has been so incredibly helpful in this regard, as it helps connect Brayden's family with others who truly understand the cruel realities of living with Barth syndrome. Although BSF is a small group, it is determined to find a cure.

Looking Ahead

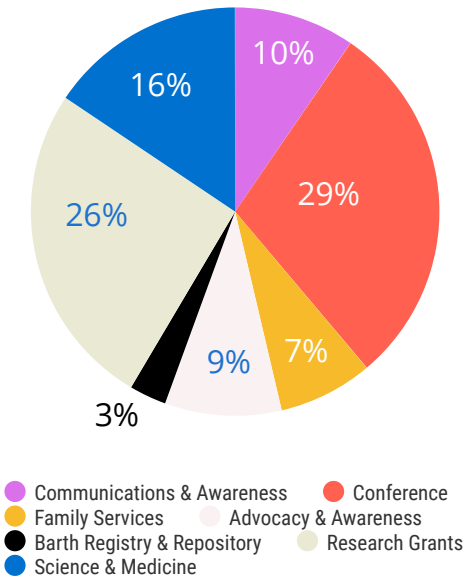
Our areas of focus over the coming year:

- Strategic pharma partnerships leading to clinical trials for people with Barth syndrome;
- Alignment of therapeutic research priorities: gene therapy, enzyme replacement therapy, modification of mitochondrial dysfunction, cardiolipin remodeling, and repurposing existing drugs for alternate applications;
- Expansion of digital communications and online interactions;
- Development of care management tools to support families in crisis.

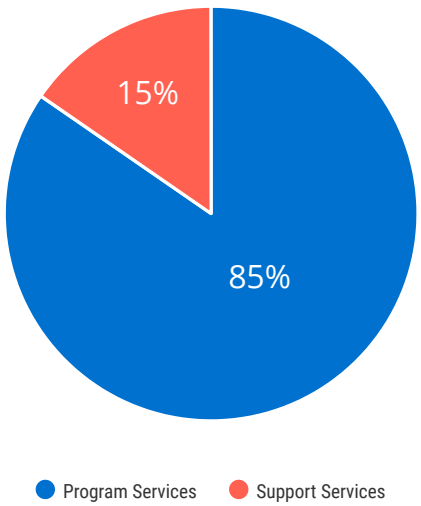
Financials

Barth Syndrome Foundation (BSF) remains a financially healthy organization, ending FY 2018 with net assets of over $4 million. This fund balance places our organization in the advantageous position of being able to encourage and even initiate development of new potential treatments. Some of these — such as gene therapy — are in our future and are likely to be a material draw on our assets. Thank you, our donors, for your generosity in helping us reach our vision: a world in which Barth syndrome no longer causes suffering or loss of life.

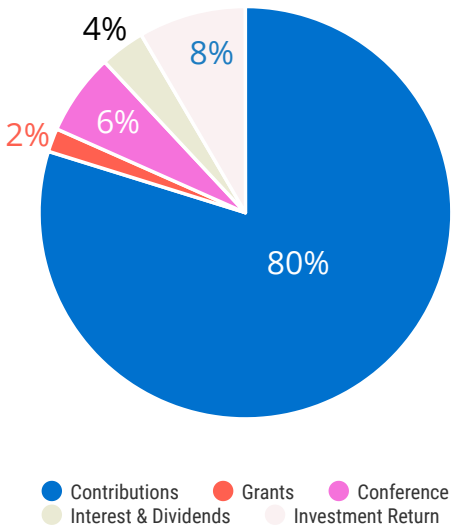
Program Expenses



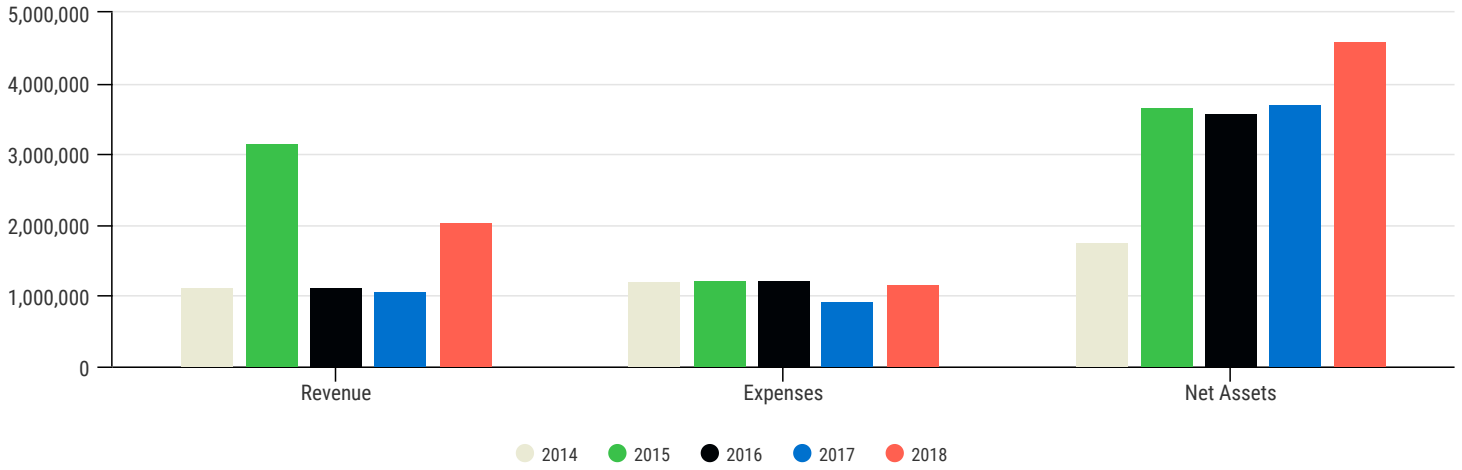
Expenses



Revenue Sources



5-year Financial Analysis



For our audited financials, please visit [barthsyndrome.org/financials.](barthsyndrome.org/financials)

Global Affiliates

The Barth Syndrome Foundation is an international organization that supports families living in any country, knowing as we do that it is only through this unified approach that we can succeed in achieving our vision. Together, we continue to generate a positive force to ensure that Barth syndrome no longer causes suffering or loss of life.

Barth Syndrome Foundation of Canada

Telephone: 1-888-732-9458 or 905-873-2391
Website: www.barthsyndrome.ca

Barth Syndrome Trust (UK)

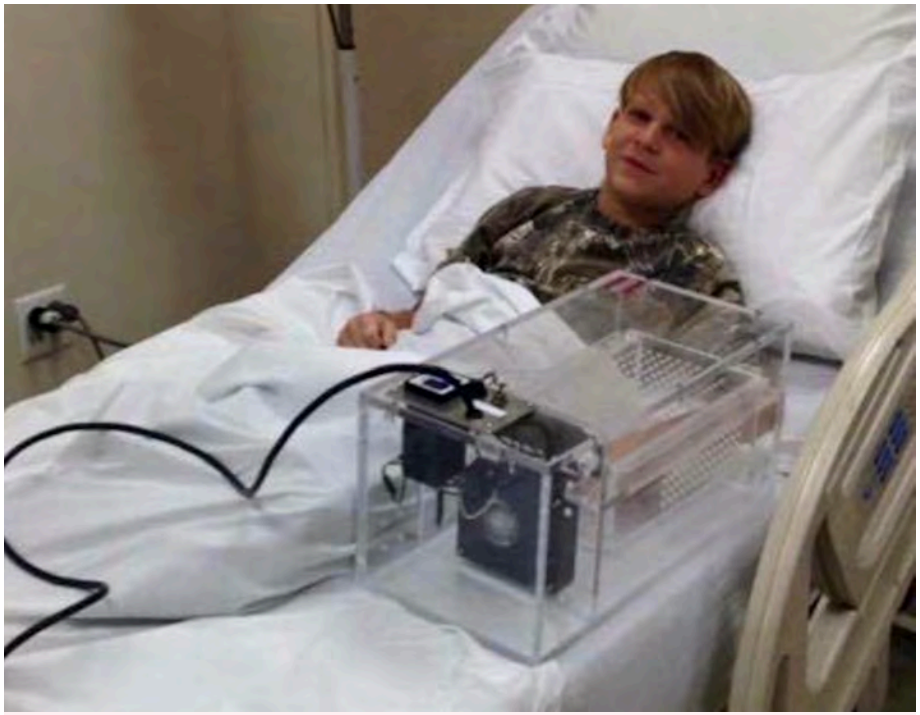
Telephone: +44 1794 518 785
Website: www.barthsyndrome.org.uk

Association Syndrome de Barth France

Telephone: +33 6 15 58 02 32
Website: www.syndromedebarth.fr/

Barth Italia Onlus (Italy)

Telephone: +390392023777
Website: www.barthitalia.org



"Awesome group of people who are dedicated to new treatments and support for each and every patient and family. Small but mighty group! If I had to live this life without them, it would be devastating."

- Amy, mom of Jacob (18)

Why give to BSF?

My daughter is a carrier of Barth syndrome, and so my journey into the world of chromosomes and genetic inheritance is somewhat different from the experience of our families who have or have had loved ones who suffer from Barth syndrome. Sometimes people ask me why I choose to be so involved with BSF since my children do not have Barth syndrome. My response is simple and heartfelt: I believe profoundly in this cause.

I have never been more encouraged by the work of a global community, or more impressed by the tenacity, focus, and diligence of collaborations between researchers and families as I am by those of BSF. Coming from a highly professional corporate background, I know that while intentions are nice, actions are crucial for meaningful progress toward a goal. In this organization, action is everything.

BSF is changing lives each and every year. The strides we made in 2018 by hosting a Patient-Focused Drug Development Meeting with FDA, completing our first Barth syndrome clinical trial, and hosting the most successful family/research conference ever were not coincidental; they were strategic and intentional.

We remain laser-focused on our mission and ethically scrupulous in the manner in which we choose to allocate funds in order to discover viable therapies for Barth syndrome.

One by one, we are building a robust community of steadfast supporters. I hope with all my heart that you will join Team Barth and the BSF Family.

Susan A. McCormack, Board Chair

"Our son Wally has Barth syndrome and without the Barth Syndrome Foundation we would have not made it these past eight months! The people are amazing and the work they do … to help find a cure for our boys … well, there aren't enough words. We love the Barth Syndrome Foundation and our Barth family!!"

– Kelsey, mother of Wally (1 year old)

Here's How You Can Help

Our amazing community brings us closer to curing Barth syndrome. Through creative and unique campaigns, our community helps Barth Syndrome Foundation support lifesaving research, raise awareness, and educate others. Here's how you can help!

DONATE

For 19 years, BSF has been a lifeline for those who suffer from Barth syndrome, offering 24/7 support, pioneering standards of care and diagnosis, creating collaborations between clinicians, researchers, and patients, and most importantly, making sure no person with Barth syndrome is ever alone. You can donate in honor or in memory of someone, to a specific fund, or to a BSF affiliate. Donate here: **barthsyndrome.org/donate**

STAY INFORMED

Although Barth syndrome is rare, our community is growing. Every year we welcome new families and supporters like you. Please subscribe today to receive email newsletters so we can keep you informed of events, opportunities to help, and exciting research updates. Visit **barthsyndrome.org/gogreen** to sign up.

FUNDRAISE

Whether you've hosted fundraising events in the past or are new to fundraising, BSF's Fundraising Toolkit is designed to help you effectively raise money and awareness. Create your personal fundraising page here: **TeamBarth.barthsyndrome.org/2019**

SHARE THE WORD

Use your social media to share your story and raise awareness about Barth syndrome. Visit our Facebook page: **www.facebook.com/barthsyndromefoundation**; our Twitter page: **twitter.com/barthsyndrome**; and Vimeo: **vimeo.com/barthsyndrome**. Use the hashtags #PowerUpBSF, #BarthSyndrome, and #TeamBarth.

SUPPORT BARTH SYNDROME RESEARCH

Everyone in the community is integral to the realization of our mission, and it starts with supporting research. From generous contributions to participation in clinical trials, we cannot do it alone. For more information: **barthsyndrome.org/research/**.

"This organization (BSF) has done everything, if not more, to try and find a cure and is still searching. This organization needs more help in research to carry on this search for the cure. This disease is very rare and deadly, so please help this organization. They are worth every penny."

- Shawana, mom of Marius (5)

Thank You

We believe the most efficient way to finding a cure for Barth syndrome is by directing as much funding as possible to research, while providing patient support and education, and tirelessly advocating on behalf of patients. Your support is greatly appreciated.

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