2022 ANNUAL REPORT

Barth Syndrome Foundation®

Our Mission

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

Our Vision

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

Our Core Values

Credibility| Integrity | Inclusion| Professionalism| Compassion

Contents

Welcome

Dear Barth Families, Friends, and Partners,

BSF has always punched above our weight, but in no year more so than 2022. Early in the year, we were still in a global pandemic that completely altered life as we had known it. What did not change, though, was our sense of urgency. Rather than hibernating or slowing down, BSF hit the accelerator. In this annual report, we share with you examples of some of our most notable accomplishments across key areas of our mission – family services, research and development, and advocacy. To say we are proud of these initiatives is nothing short of an understatement, and we hope you celebrate these successes with us.

Living with a medically complex disease, such as Barth syndrome, is predictably uncertain. A day can begin like any other and end with life hanging in the balance. Perhaps it is this uncertainty that has made our community inordinately persistent and resilient. As the pandemic generated uncertainty and concern (especially for our immunocompromised community), we were forced again to cancel our international conference. We were disappointed yet not disheartened. Our families pleaded for togetherness beyond a distant voice on the telephone or a face on a Zoom meeting, so we pivoted and created our “Stronger Together World Tour.” In partnership with our international members and affiliates, we brought together more than 180 people gathering in small groups regionally at 7 places around the world, including Calgary, CA; Heilvort, NL; Leicester, UK; and across the US. Families tapped into this lifeline of support, education, fun and strengthened community.

In parallel, we fostered collaborations across our research community to keep the science of Barth syndrome advancing despite pandemic challenges. For three days in July 2022, we convened almost 150 clinicians and researchers from around the world online for our 2nd Scientific and Medical Virtual Symposium. Sessions were devoted to sharing findings on key pathologies driving Barth syndrome research and providing updates on therapeutic development activities that BSF is laser-focused on advancing. The meeting was proclaimed a huge success, as participants reported that it offered excellent content and generated new ideas, advanced former ones, and encouraged additional investigators to focus on our disease.

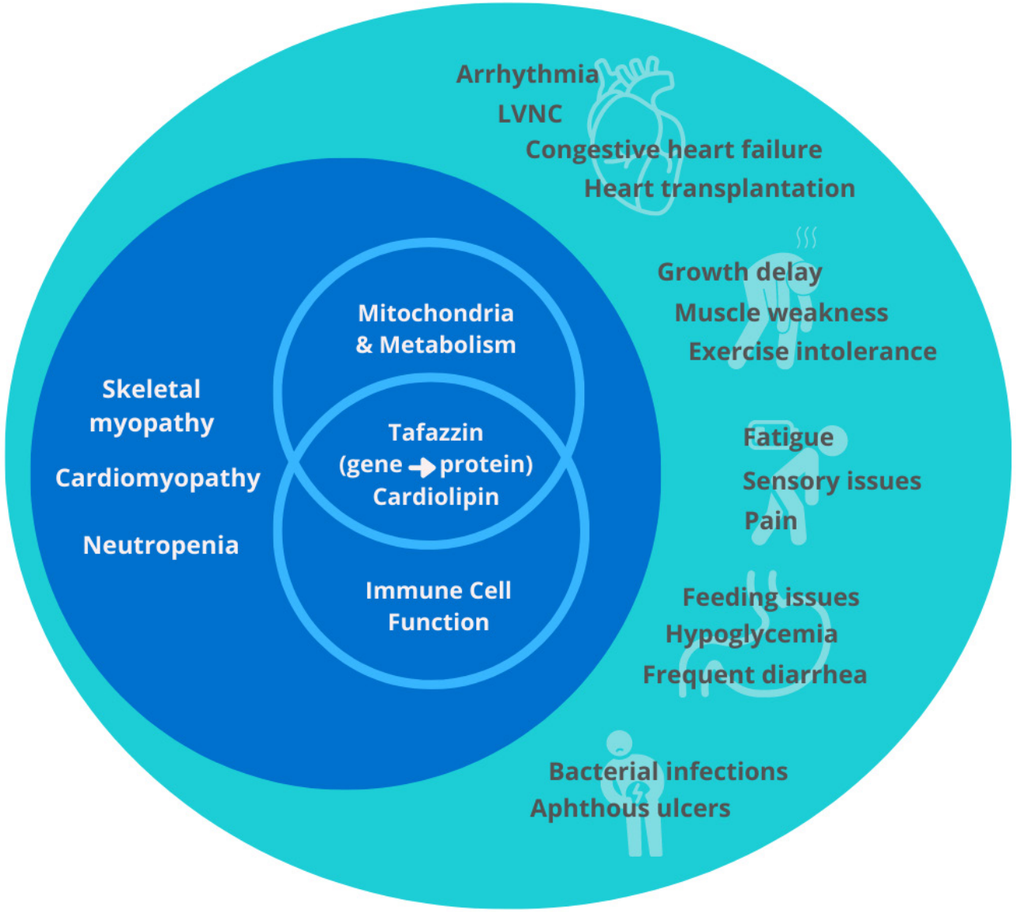
As we have found, the existence of safe and promising therapies doesn’t guarantee that treatments will be approved. For this reason, in July BSF held an unprecedented half-day workshop with more than 40 officials from the US Food and Drug Administration (FDA). The meeting focused on educating regulators about Barth syndrome, the extreme unmet medical need of our patients, and the significant inherent challenges that every ultra-rare disease faces due to the extremely limited number of patients who can participate in clinical trials. Barth clinical experts joined BSF in these important conversations that we hope will solidify groundwork on which the FDA can make informed decisions about therapies for Barth syndrome and pave possible regulatory pathways forward for many ultra-rare diseases.

Every day we give thanks for the people who make BSF the extraordinary foundation that it is. To the donors who help finance our critical initiatives, to the families who are unwavering in their engagement, and to the volunteers who give of their time and talents toward our mission, we thank you and look forward to continued partnership in the years to come.

Emily Milligan
Executive Director

Kate McCurdy
Board Chair

What is Barth Syndrome?



Barth syndrome is a rare, life-threatening, genetic mitochondrial disorder primarily affecting males. 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, extreme 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.

Who We Are

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. To achieve this goal, BSF has invested $5.85M USD in research, which has translated into $32.7M in follow-on funding from other agencies and catalyzed another $6.7M USD for clinical trials research.

BSF AFFILIATES

Barth Syndrome Foundation of Canada
Phone: 1-888-732-9458 or 905-873-2391
www.barthsyndrome.ca

Syndrome de Barth (France)
Phone: +33 6 15 58 02 32
www.syndromedebarth.fr

Barth Syndrome UK
Phone: +44 1794 518 785
www.barthsyndrome.org.uk

Barth Italia Onlus (Italy)
Phone: +390392023777
www.barthitalia.org

Investing in Research & Development

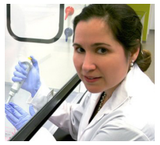
Research & Development Goals

- Continue to fund discovery research and tools to improve our understanding of Barth syndrome
- Invest in a natural history study to make it easier for potential partners to work with us on our ultra-rare disease
- Focus resources on specific research areas, including drug repurposing & disease management, that can improve treatment options for Barth syndrome
- Pursue collaborations that allow us to advance gene therapy and enzyme replacement therapies

Learn more

From Our Researchers

Supported by BSF's grant program, these publications demonstrate the continued progress of scientists and clinicians in understanding the biology that drives Barth syndrome and its impact on the quality of life of affected individuals. In their own words the authors share the impact of their work on the Barth syndrome community.



N-oleoylethanolamide treatment of lymphoblasts deficient in Tafazzin improves cell growth and mitochondrial morphology and dynamics

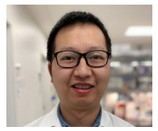
"A number of researchers are working to find new therapies for Barth syndrome, and having the Tafazzin knockout mouse model provides an incredible resource to accelerate this work. Our publication characterizes the mice at 3 different ages, giving information on both the magnitude of differences between the mice and their littermates, and the timeline of changes in the mice, which we hope will help researchers to select the best targets when testing new treatments."
-**Dr. Robin E. Duncan**

Barth syndrome: psychosocial impact and quality of life assessment

"Our study provides valuable information regarding quality of life in patients with Barth syndrome. We feel that this highlights another opportunity to offer comprehensive care to the patients and families living with this impactful disease. The data should provide opportunities for future and much-needed investigation which can further delineate the psychosocial impacts and quality of life implications of Barth syndrome."
-Dr. John L. Jefferies and **Dr. Anandbir Bath**

A new murine model of Barth syndrome neutropenia links TAFAZZIN deficiency to increased ER stress-induced apoptosis

"Neutrophils are a type of white blood cell that is challenging to study, making it all the more difficult to understand why people with Barth syndrome can develop neutropenia. In our publication, we established a new research tool that we hope can accelerate research around understanding Barth syndrome neutropenia."
-Dr. David B. Sykes



A simple mechanistic explanation for Barth syndrome and cardiolipin remodeling

"In our study, we found that defective mitophagy caused by Tafazzin deficiency leads to accumulation of dysfunctional mitochondria in cells. Restoration of mitophagy by inhibition of mTORC1 mitigates cardiomyopathy in a mouse model of Barth syndrome, implicating novel therapeutic targets for the treatment of Barth syndrome."
-Dr. Jun Zhang

Investments in Research

Our investments in Research & Development (R&D) demonstrate BSF's unrelenting commitment to identifying potential treatments and better understanding the challenges experienced by our community of affected individuals. These projects are vetted by BSF's Scientific and Medical Advisory Board alongside external reviewers and experts.

Investigating the basis of neutropenia in Barth syndrome

Idea Award, $49,999 over one year

Borko Amulic, PhD
University of Bristol

Awarded to Dr. Borko Amulic and Dr. Colin Steward, this project takes advantage of proximity to the National Health Service (NHS) Barth Syndrome Service at Bristol Royal Hospital for Children to investigate primary neutrophils and their progenitors from Barth syndrome patients. First, this effort will investigate development and differentiation of Barth syndrome neutrophils from circulating stem cells under conditions of inflammatory and metabolic stress. Secondly, it will examine how hyperdegranulation affects the interaction of Barth syndrome neutrophils with the endothelium both ex vivo and in a mouse model of Barth syndrome.

This project's funding was made possible by generous contributions from our affiliates Barth Syndrome Foundation of Canada and the Barth Syndrome UK.

Feeding the starving heart in Barth syndrome

Development Award, $82,400 over two years

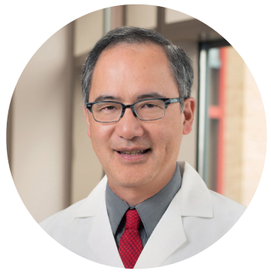
Adam Chicco, PhD
Colorado State University

Awarded to Dr. Adam J. Chicco, this project will test the hypothesis that providing alternative fatty acid fuels that bypass the long chain fatty acid (LCFA) oxidation system will improve exercise tolerance and cardiac functional capacity in Barth syndrome patients. Using the two tafazzin-deficient mouse models of Barth syndrome currently available, this effort will determine if therapeutic doses of triheptanoin, a synthetic shorter-chain fatty acid supplement recently FDA-approved for treatment of LCFA oxidation disorders, improves exercise capacity, cardiac function, and mitochondrial metabolism. If successful, these results will provide the basis for exploring for the clinical exploration of this supplement in Barth syndrome patients.

This project's funding was made possible by the generous support of the Will McCurdy Fund for Advancement in Therapies for Barth Syndrome.

Enzyme replacement therapy for Barth syndrome

Strategic Initiative, $25,000 over one year



Invested in Dr. Michael Chin and TransCellular Therapeutics (TCT), this partnership seeks to advance enzyme replacement therapy for Barth syndrome and bring this approach one step closer to clinical investigation. Building upon research first conducted at the University of Washington, and now under development at Tufts Medical Center, the goal of TCT's recombinant tafazzin enzyme replacement therapy is to deliver enzyme into the mitochondria of affected cells and tissues to ameliorate the symptoms associated with Barth syndrome.

Michael T. Chin, MD, PhD
Tufts University

Optimization of Barth syndrome gene therapy

Strategic Initiative, $68,750 over one year

Granted to Dr. William Pu, this effort seeks to optimize the gene therapy package for Barth syndrome gene replacement therapy, including the promoter, gene, expression cassette, and capsid. The optimized package will then be tested for efficacy in the Barth syndrome knockout mouse model, seeking to maximize the durability and efficacy while minimizing the potential adverse reactions of this therapeutic approach.

This project's funding was made possible by generous contributions from our affiliate Barth Italia Onlus

William Pu, MD
Boston Children's Hospital

ALCAT1 as a novel target for the treatment of cardiomyopathy in Barth syndrome

Development Award, $100,000 over two years

Awarded to Dr. Jun Zhang, the proposed studies will determine the role and underlying mechanisms of ALCAT1 as a key regulator of mitochondrial dysfunction in Barth syndrome, further building on past BSF support for this hypothesis. This project will also validate inhibition of ALCAT1 by a small molecule inhibitor as a novel and potential treatment for cardiomyopathy in Barth syndrome.

This project's funding was made possible by the generous support of the Will McCurdy Fund for Advancement in Therapies for Barth Syndrome.

Jun Zhang, PhD
University of Texas Health Science Center at San Antonio

A Greater Understanding of Barth Syndrome

Convened on July 20-22, 2022, BSF held our second virtual Scientific and Medical Symposium spanning Barth syndrome cardiomyopathy, treatment for & quality of life of Barth syndrome patients, Barth syndrome biology, Barth syndrome in physiology, and cardiolipin in physiology.

With over 100 unique views each day and composed of presenters and attendees from all across the world, this event demonstrated the global scope of the Barth syndrome community of patients, families, researchers, and clinicians.

Meet the Presenters

Jim Carr
Stealth BioTherapeutics

Michael T. Chin
Tufts Medical Center

Jan Dudek
University of Würzburg

Robin E. Duncan
University of Waterloo

Brittany Hornby
Kennedy Krieger Institute

Elizabeth Jennings
University of Nevada, Reno

Markus Keller
Medical University of Innsbruck

Colin Phoon
NYU Langone Health

Stacey Reynolds
Virginia Commonwealth University

Mack Reynolds
University of Michigan Medical School

Nanami Senoo
Johns Hopkins University

Reina Tan
NYU Langone Health

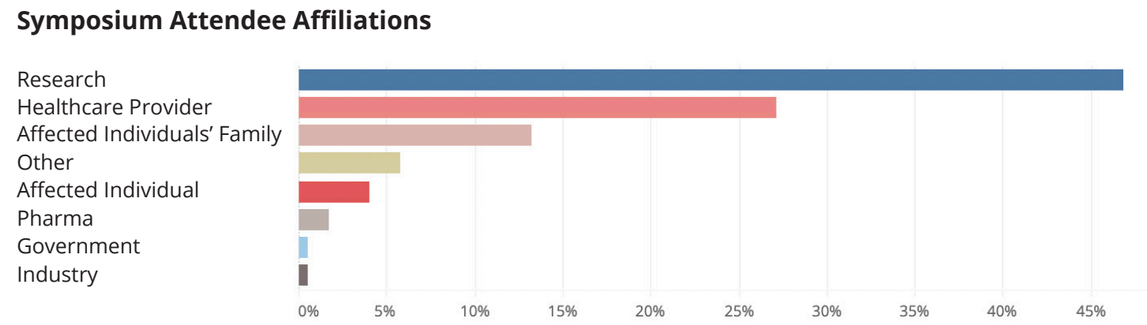
Carolyn Taylor
Medical University of South Carolina

Linh Vo
Wayne State University

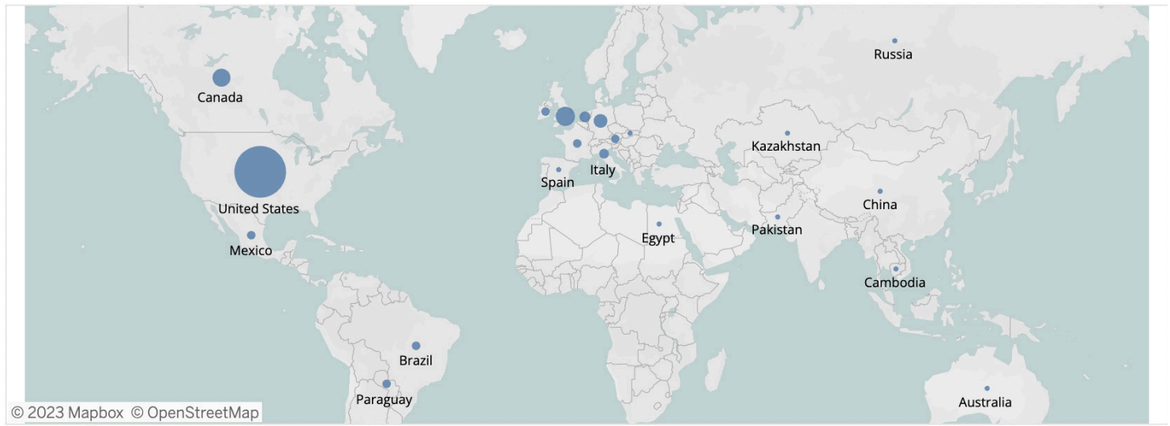
Suya Wang
Boston Children's Hospital

Jessie Yester
Nationwide Children's Hospital

142 Unique Attendees



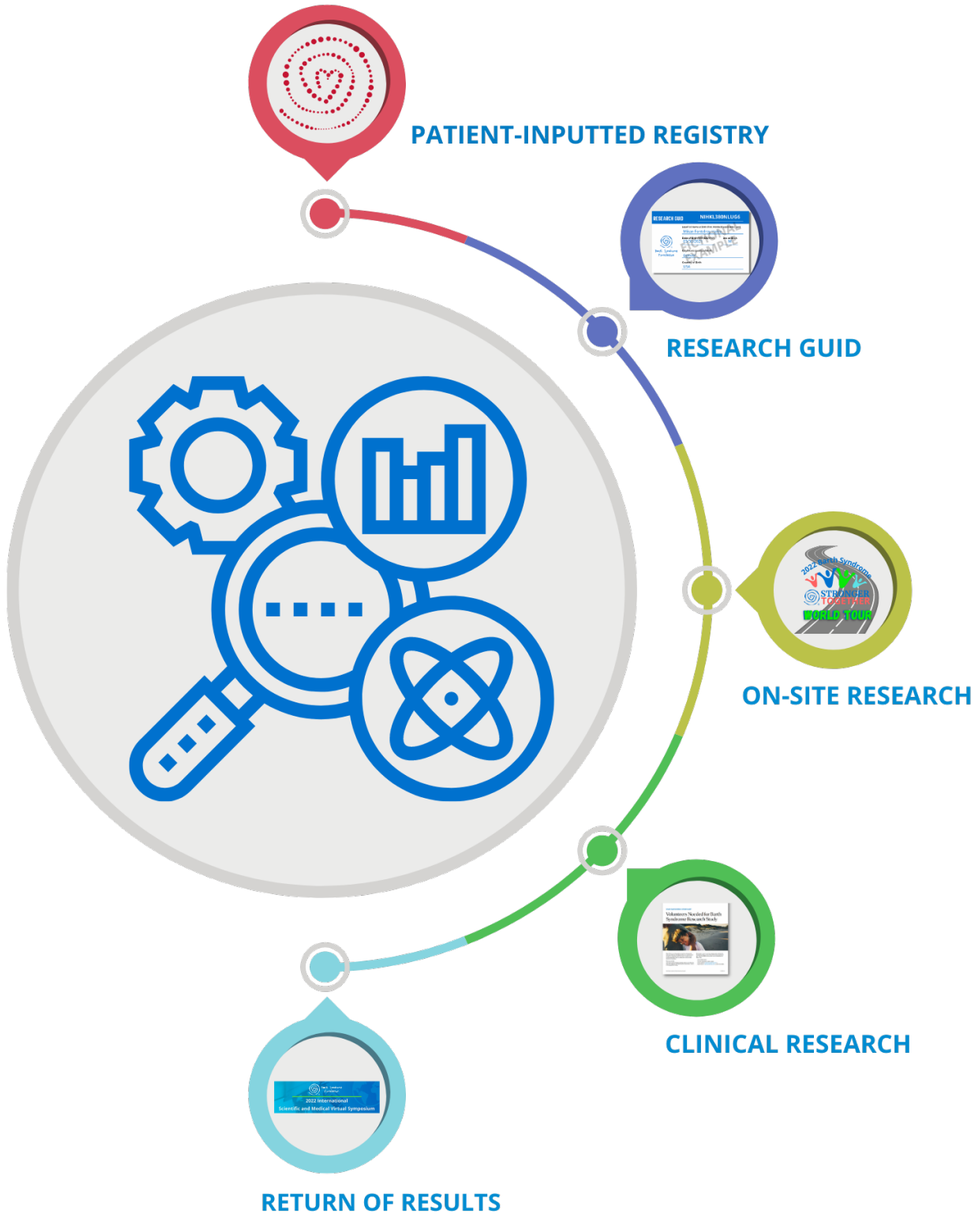
From Across the Globe



Watch the recordings of the entire symposium:

Research Engagement & Recruitment

BSF's Research Engagement & Recruitment efforts are the centerpiece collaboration between R&D and Family Services Programs. Affected individuals and families contribute vital data through the Patient-inputted Registry, enrolling in the Research Global Unique Identifier (GUID), and volunteering in clinical studies to advance possible treatments for Barth syndrome.



Reach Out

When an affected individual or family member chooses to engage with BSF, we enroll them in our patient registry so we can learn about their unique experience with Barth syndrome. We also create a Research GUID card they use to join other studies and share data securely.

Participate

Research participation can happen in a variety of ways, at home, at the 2024 International Conference, or at a research center or hospital.

Inform

The results of study participation will be disseminated back to the individual. We also ask researchers to present their findings at our Research Roundtables or at the Virtual Symposium or International Conference.

25% **of eligible individuals received their GUID Card in 2022**

The Brody Family

"The GUID cards worked wonderfully and got us all set up for the research study!"

John Wilkins

"The GUID is wonderful. It will allow researchers to share data. This will prevent repetitive testing across research projects. Obtaining and using the GUID is very simple; it will be an excellent tool in our toolbox."

Supporting Our Community

Supporting Barth Family Goals

- Make it easier for families to access critical information about Barth syndrome
- Bring in outside experts that can help affected individuals and families better understand the disease
- Be there for affected individuals & families when they are scared, unsure, or in the middle of a crisis
- Connect families across the world through our conference, outreach events, and online communities
- Include affected individuals in opportunities to help steer our future

Learn more

Being There for Affected Individuals and Families

In 2022, BSF's Barth Cares program launched our Barth Syndrome Emergency Relief Program administered through the National Organization for Rare Disorders (NORD). The Emergency Relief program is designed to provide assistance to families who are facing financial hardships due to the medical expenses associated with Barth syndrome. The program is entirely funded by donations, and all funds go directly to individuals and families in need.

BSF seeded

$17,500

emergency funding for affected individuals & families

"When your complex child is hospitalized with a life-threatening illness things are stressful enough. Then comes missed work resulting in unpaid bills. Thanks to BSF Emergency Relief Program that was one less burden. The process was simple and really helped us to be able to focus on the most important aspects of these hospitalizations, our son."
-Parent of young boy with Barth syndrome

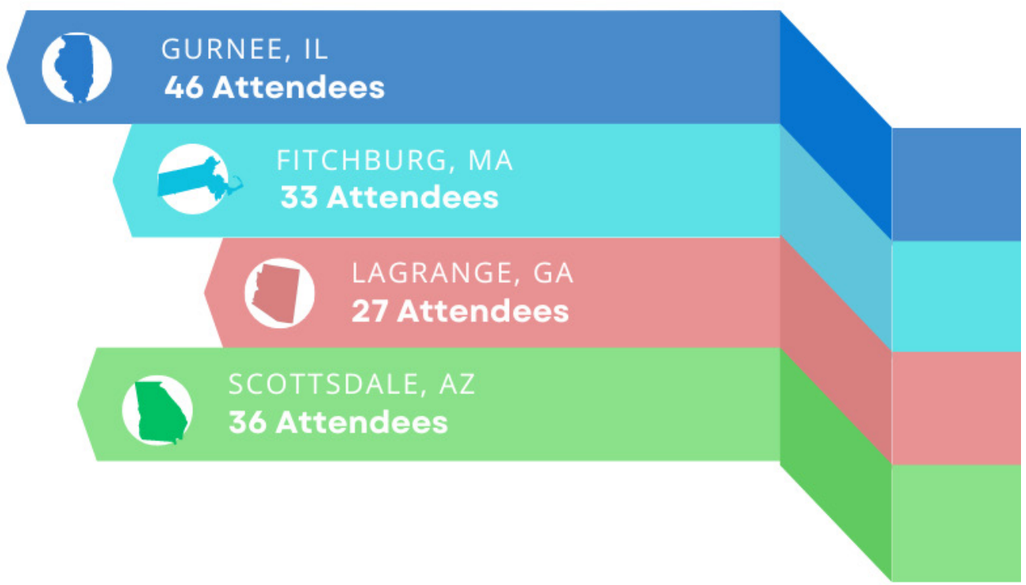
Connecting Families Across the World

Historically, the Barth community gathered every two years for the International Scientific, Medical, and Family Conference for five or six days of meetings, gatherings, and comraderie. However, the global pandemic necessitated the postponement of the 2020 conference to 2024. The Stronger Together World Tour was designed to bridge this gap in a meaningful and safer format. These smaller gatherings were strategically located to reduce the amount of travel exposure for attendees while still providing activities and learning opportunities. The 2022 US Tour had stops in Fitchburg, MA; Gurnee, IL; LaGrange, GA; and Scottsdale, AZ, with international stops in the UK, the Netherlands, and Canada.

12 **New US families met the community in-person for the first time**

2022 Barth Syndrome STRONGER TOGETHER WORLD TOUR

142 Total US Attendees



"It was so much fun and meant so much to finally meet the people who have been family for years in person. We had a ball, and we love you all!" -**Ayana P**

"It's always powerful when you can be with others who share the same struggles and triumphs. Sharing our stories, being supported, encouraging one another is what I love most." -**Tracy B**

"Words cannot describe how amazing it was to see some of our Barth family at the Stronger Together World Tour 2022... and a BIG thank you to BSF for always hosting the most amazing events." -**Kelsey B**

Educating Our Community

BSF and the National Neutropenia Network joined forces in 2022 to organize a groundbreaking educational series on neutropenia, a part of Barth syndrome. Neutropenia is a rare and potentially life-threatening condition characterized by abnormally low levels of neutrophils, a type of white blood cell crucial for fighting off infections. This collaborative effort aimed to raise awareness about neutropenia, provide valuable information to patients and their families, and foster a supportive community.

Research Updates

Virtual open meetings discussing the latest Barth syndrome research

4
Sessions

Fact Sheets

Ever growing library of resources detailing aspects of Barth syndrome

25+
Available

Newsletter

News and education delivered throughout the year electronically and postal mail

2000+
Subscribers

Friday Roundtable

Virtual educational sessions with experts in the field

120+
Views

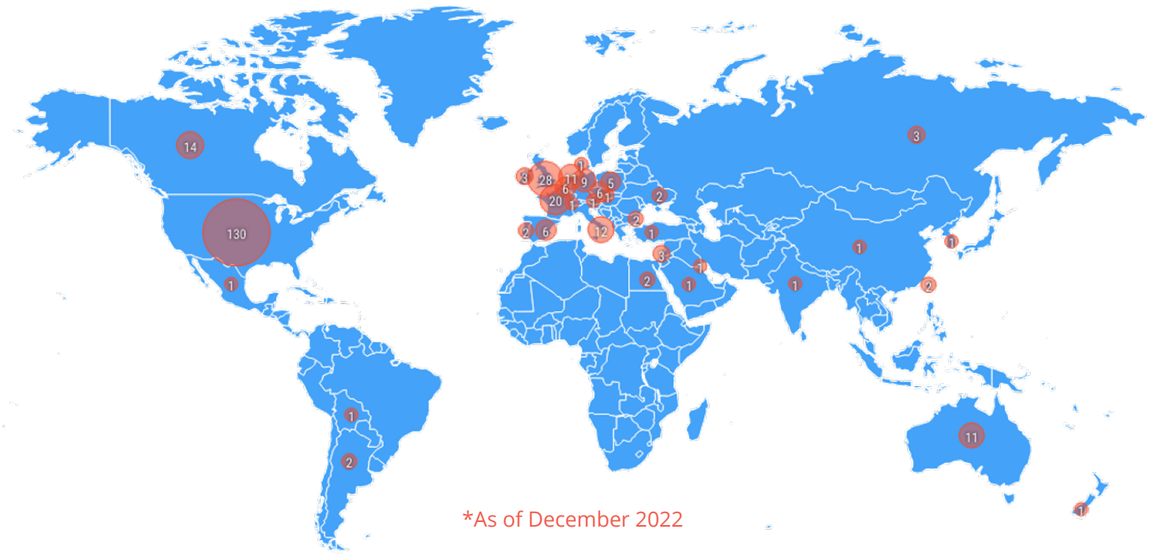
Family Chat

Private Facebook group as a forum for communal education and support

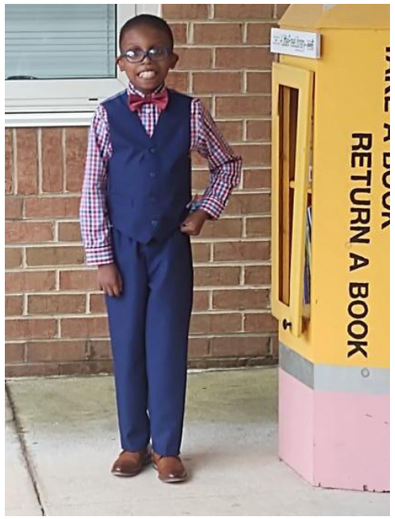
474
Members

Barth Strong

300 Individuals Living with Barth Syndrome Worldwide*



*As of December 2022



"My name is Quentin and I have been living with Barth since birth. I'll be 11 in December [2022]. I didn't understand it much when I was younger but as I've advanced in school, I understand how different I am to the kids in my class. They call me small, or say I can't run fast, and sometimes it is hard to make friends. I really wish I didn't have this condition. I hope a cure is discovered someday. The Barth Syndrome Foundation helps my mom educate my teachers, schools, and local doctors."

Advocating for Our Community

Strategic Advocacy Goals

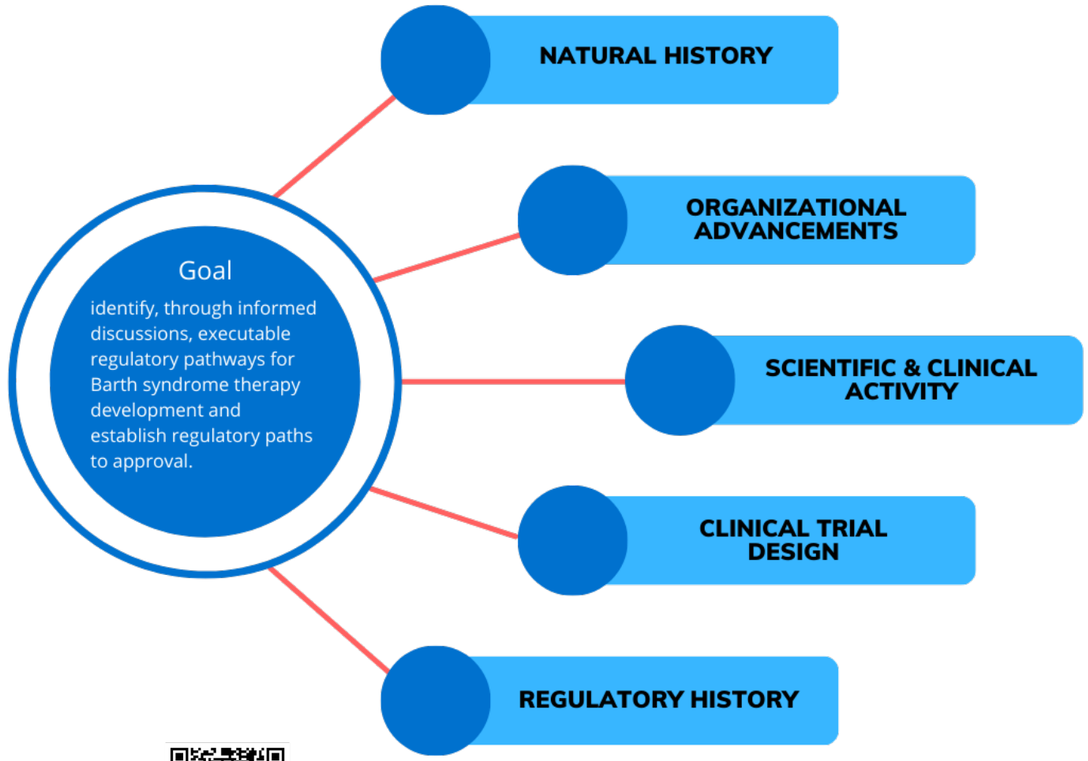
- Give members of our community the tools they need to champion our cause
- Promote the interests of our community with state and federal legislators
- Generate external interest by sharing community stories and the science of Barth syndrome
- Involve ourselves in product development and regulatory processes when we believe it will help
- Fund a health impact study and educate payors to improve access to care

Learn more

Promoting Community Interests with Legislators

BSF, including BSF representatives and key clinical disease leaders, held an important workshop with Dr. Norman Stockbridge, Director of the Division of Cardiology and Nephrology in the Center for Drug Evaluation and Research at the US Food and Drug Administration (FDA), and over 30 other representatives of different FDA centers, offices, and divisions on July 29, 2022. The stated purpose of this workshop was "to identify, through informed discussions, executable regulatory pathways for Barth syndrome therapy development and establish regulatory paths to approval." It was a rare opportunity to further educate the FDA about disease-specific details of Barth syndrome and to initiate work that we hope ultimately will lead to consensus about possible paths forward for future approved treatments for our ultra-rare disease.

Goal and Key Points of Discussion



Learn more

Champions of Our Cause

We at BSF express our heartfelt gratitude to Bryan D, Steven G and Walker B for meeting with legislators in their home States in 2022. All three volunteer ambassadors participated in a national campaign for better US Food and Drug Administration (FDA) review processes for ultra-rare indications, like Barth syndrome.

"It's incomprehensible that the drug has not been approved yet... I feel my words are falling on deaf ears with the FDA. I've used terms like the "old Walker" vs the "new Walker" as I truly feel like a new person after being on an experimental therapy for more than 4 years [...] My energy, my strength, my quality life, even just the way I look at life now has completely changed [...] I can't fathom life without this drug."

Walker B, Affected Individual

"We simply cannot comprehend why FDA holds ultra-rare disease populations to the same definitionally impossible standards as they do with diseases like cancer that affect tens and hundreds of thousands of people. We need Accelerated Approval by the FDA to realize the first-ever life-enhancing therapy for our boys with Barth syndrome."

Bryan D, Parent of Affected Individual

"I'm lucky to be here," said 35-year-old Steve G, "since so many people with this disease die very young.... If you are blessed enough to get to adulthood, you often require a heart transplant or suffer from debilitating conditions [...] Taking two or three steps can cause shortness of breath, tiredness, and leg muscle pain."

Steve G, Affected Individual

Progressing our Mission

Happy Heart Week is an annual awareness and fundraising campaign championed by BSF Board Member, Megan Branagh. The week-long celebration is in honor of her son, Henry, who is living with Barth syndrome. For Henry's milestone 10th birthday, this year's celebration culminated in an in-person party, bringing together family, friends, and supporters to help drive BSF's mission.

Over
A Quarter Million Dollars
Raised

www.happyheartweek.com

Generating External Interest

The NY Islanders who have been a long-time supporter of BSF and our mission, agreed to honor BSF and a representative of the Barth syndrome community - 5 year-old Thomas - at their March 19th, 2022 game against the Dallas Stars. As every Barth family knows, Barth syndrome is unpredictable and can change plans in an instant. Thomas unfortunately couldn't be at the game, but his dad took up the flag in his honor.

Thank you to Thomas and his family, everyone who donated, and the NY Islanders owners, Jon Ledecky and Scott Malkin, who made this possible!

$100,000

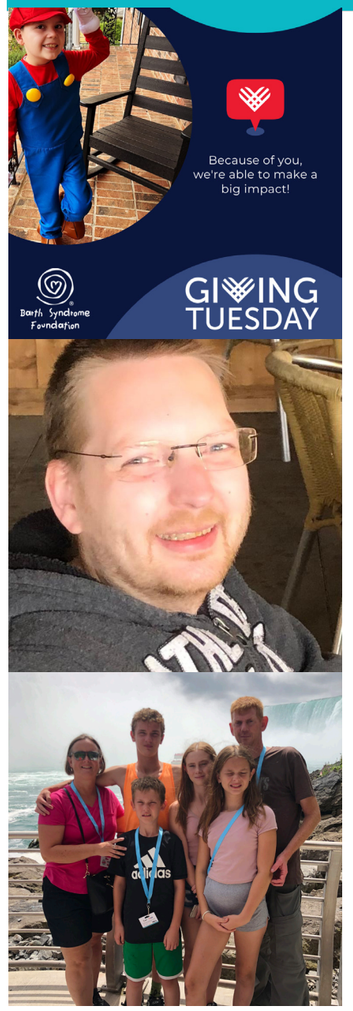
In donations

including a

$50,000

Anonymous Match

Funding Our Mission



2022's Giving Tuesday was our biggest year ever! These mission-critical dollars fund research, support advocacy, and help families and people with Barth syndrome.

$123,000

Raised

600+

Donors

50+

Fundraisers

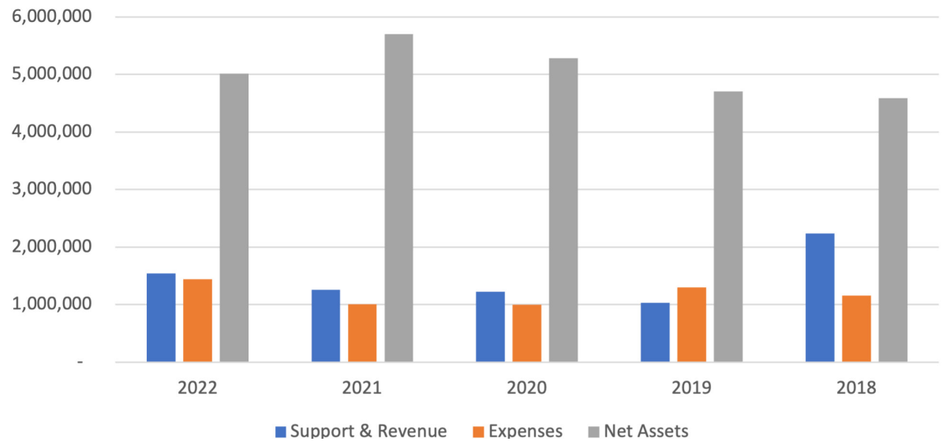
Statement of Financial Activity

BSF remains a financially healthy organization that continues to encourage and initiate research and development of potential new treatments. Thank you to our donors for your continued support in helping us work toward our vision-- a world in which Barth syndrome no longer causes suffering or loss of life.

Public Support & Other Revenue	
Contributions	$1,327,138
Contributions of Nonfinancial Assets	$77,451
Grants	$70,000
Interest & Dividends (net of fees)	$71,589
Total Support & Revenue	**$1,546,178**
Expenses	
Communications & Awareness	$90,746
Conference/Regional Meetings	$65,922
Family Services	$111,467
Advocacy & Awareness	$113,967
Barth Registry & Repository	$18,141
Research Grants	$302,773
Science & Medicine	$327,973
Administration	$252,372
Fundraising	$161,417
Total Expenses	**$1,444,778**
Realized & Unrealized Investment Gains/(Losses)	**$(789,759)**
Change in Net Assets	**$(688,359)**
Assets	
Cash	$686,513
Investments- General	$4,515,032
Investments- Strategic	$25,000
Grants Receivable	$103,000
Prepaid Expenses	$42,455
Total Assets	**$5,372,000**
Liabilities	
Accounts Payable & Accrued Expenses	$88,438
Deferred Revenue	$27,183
Research Payable	$243,049
Total Liabilities	**$358,670**
Net Assets	
Without Donor Restrictions	$998,736
With Donor Restrictions	$4,014,594
Total Net Assets	**$5,013,330**
Total Liabilities & Net Assets	**$5,372,000**

All financials based on 2022 independent audit

5 Year Trend



Help Support BSF

Since 2000, 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.

Your support is vital to the success of our mission, so please consider making a gift today.

Donate at www.barthsyndrome.org/donate

Thank You!

We believe the most efficient way to find a cure for Barth syndrome is by directing as much funding as possible to research, providing patient and family support, and engaging in advocacy. We truly appreciate your continued support.

$25,000 +

Association Syndrome de Barth France
The David & Janyce Hoyt Foundation
Peter and Isabel Malkin
Scott and Laura Malkin
Steve and Kate McCurdy
Christopher McKown and Abigail Johnson
The National Institute Of Health
Dr. Paul S. Russell
Stealth BioTherapeutics Inc.

$10,000 +

Hon. Richard and Cynthia Blumenthal
Andrew and Anne Branagh
Bill and Nancy Branagh
Branagh Holdings Inc
Branagh, Inc.
Tom and Diane Branagh
Jeffrey Griffith
Barth Italia Onlus
Jill and Matt Korpita
Matt and Suzanne Kroger
Bradley and Gaylord Lummis
Marilyn Lummis
Palmer and Mallory Lummis
New York Islanders Hockey Club LP
Dr. Nina Russell and Tom Rubin
Marc and Tracy Sernel
Jerry Wilkins

$5,000 +

Aegis Fire Systems
Anonymous Donors
Basco Drywall & Painting Co
Jon and Nancy Bauer
Bruce and Monica Bercovich
John and Megan Branagh
Meredith and Eugene Clapp
Amy and Burt Coombe
Tom and Carrie Cusack
Dr. Thaddeus and Louisa Fulford-Jones
Ashley Garrett and Alan Jones
Paul and Mariana Ingersoll
Denise Lascurettes and Vincent Mangiapane
Sonja and Gregor Schlapak
Brenda Shapiro
Nicholas and Allison Tarrab
UCSF Benioff Children's Hospital & Research Center at Oakland
Kevin and Stacey Woodward

$2,500 +

William and Christie Belscher
Bonfire Funds Inc.
Geoffrey and Tamara Branagh
Kate and Frank Canova
Natalie and Paul Cohn
Mary Conway and Jim Fanto
Brandi and Nick Dague
Molly and Patrick Devinger
Dillon Foundation
Julie and Will Fiske
Tim Heine
Heritage Bank of Commerce
Scott Jordan
Legacy Risk & Insurance Services
Christie and Scott Logan
Patty McCormack
Kirt and Martha Miller
Susan and Peter Osnos
Dr. Peter and Helen Randolph
Tara Smith and Dan Kacher
Natan Vaisman and Beth Roberts
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