



Barth Syndrome Foundation

2021 ANNUAL REPORT



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

Welcome

A Message to Our Community

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Dear BSF Friend,

2021 proved again that BSF and our Barth syndrome community are resilient. The year was difficult in several ways, and yet we made real advances. COVID-19 posed enormous challenges for BSF as it did for the rest of the world, but we remained committed to projects that ultimately we believe will yield significant progress. We have never, ever allowed adversity to cloud our vision. One day, this world will know treatments and a cure for Barth syndrome!

Around the globe, we demonstrated immense determination toward our mission. In 2021, we had one of the most successful fundraising years in BSF's history. Combined with strong fiscal management, we netted \$600,000 more in revenue than budgeted. This would not have been possible without our generous donors who contributed to this outstanding performance. And nearly 50 people in our small community collectively raised almost \$110,000 on Giving Tuesday, an amazing result. This and other campaigns contributed to the \$1.5 million surplus we have generated over the last three years, allowing us now to expand our research and development (R&D) efforts in much needed ways.

This strong financial position permits BSF to "punch above our weight" and to plan expensive yet necessary investments in several key strategic areas including gene therapy, cardiac management, and critical research tools. Enhancing research tools, such as our genetic variants database, and strategically de-risking early therapy development through our competitive grant program and direct contracts are among our organization's most important decisions. They represent two critical ways we are accelerating vital progress.

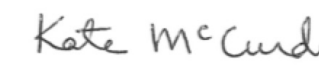
2021 also brought some setbacks. Stealth BioTherapeutics, the company testing our first potential new drug (elamipretide) in a clinical trial received a refusal-to-file letter from the FDA for their New Drug Application (NDA). Often this verdict is the end of a potential therapy, but BSF and Stealth continue to push discussions for possible solutions with regulators. Unfortunately, we recently learned that the second clinical trial for a possible treatment for Barth syndrome, this one in the UK testing a repurposed drug (bezafibrate), did not meet its clinical endpoints and therefore was unsuccessful. We fully understand that not all clinical trials yield positive results, but this was very disappointing. Even so, we keep our sights on the future and move forward with resolve to advance other possibilities in our R&D pipeline.

On a positive note, 2021 additionally marked the launch of BSF's Family Services' Barth Cares program. We always offer information, contacts and understanding counsel to affected individuals and families in need. With the help of dedicated volunteers, we expanded our services to include care packages and other gestures of support to Barth families experiencing some of the most challenging times they may ever endure. Our volunteers are the heart and backbone of BSF and help make possible these kinds of programs that show that BSF cares.

Last year proved again that "We are better together wherever we are!" We thank you for being a friend and supporter of BSF during these difficult times for our world. Together we are #BarthStrong.

In health and hope,


Emily Milligan,
Executive Director


Kate McCurdy
BSF Board Chair

OUR MISSION

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

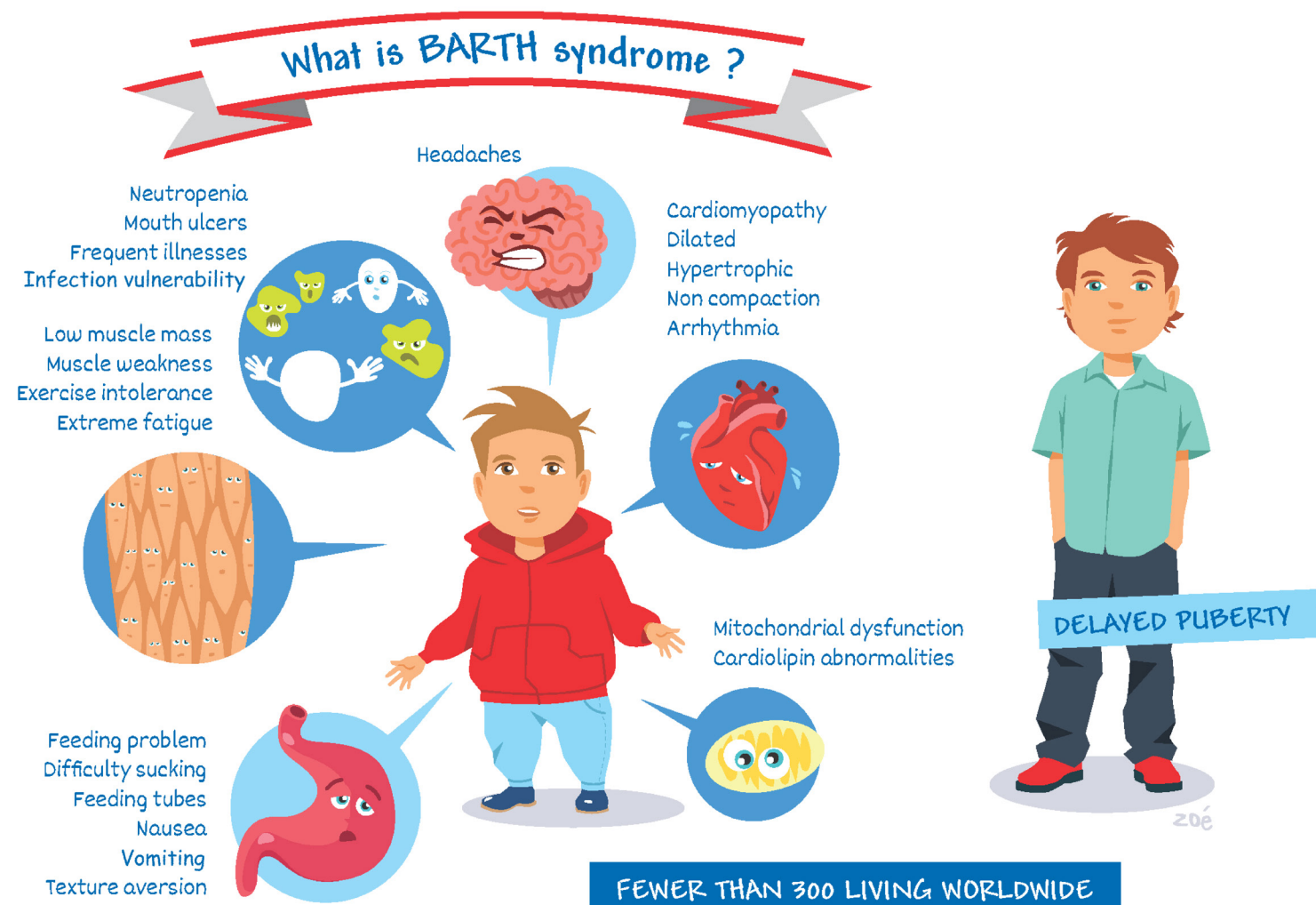
OUR VISION

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

OUR CORE VALUES

Credibility | Integrity | Inclusion | Professionalism | Compassion

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

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Strategic Plan 2021-23

“What can we do at BSF to have a real impact?” This question has been the driver of the strategic planning process. The mission and vision remain completely unchanged.

The focus areas for BSF’s strategy for 2021-2023 are: invest in research and development (R&D), support Barth families, be strong advocates for our community, and never, ever give up.

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 Strategy

We will invest in research and development (R&D), support Barth families, advocate for our community, and most importantly, never, ever give up!

Invest in R&D

We will make smart investments in research that can improve our understanding of Barth syndrome, identify possible treatments, and develop a cure.

- 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.
- 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.

Support Barth Families

Through all the ups and downs, we stand with our families, and offer the resources and compassion they need to navigate life with Barth syndrome.

- Make it easier for families to access critical information about Barth syndrome.
- Bring in outside experts that can help affected individuals and families.
- 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.

Advocate for Our Community

Barth syndrome is rare, and we do everything we can to make our voice heard and attract support and focus to our cause.

- 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.

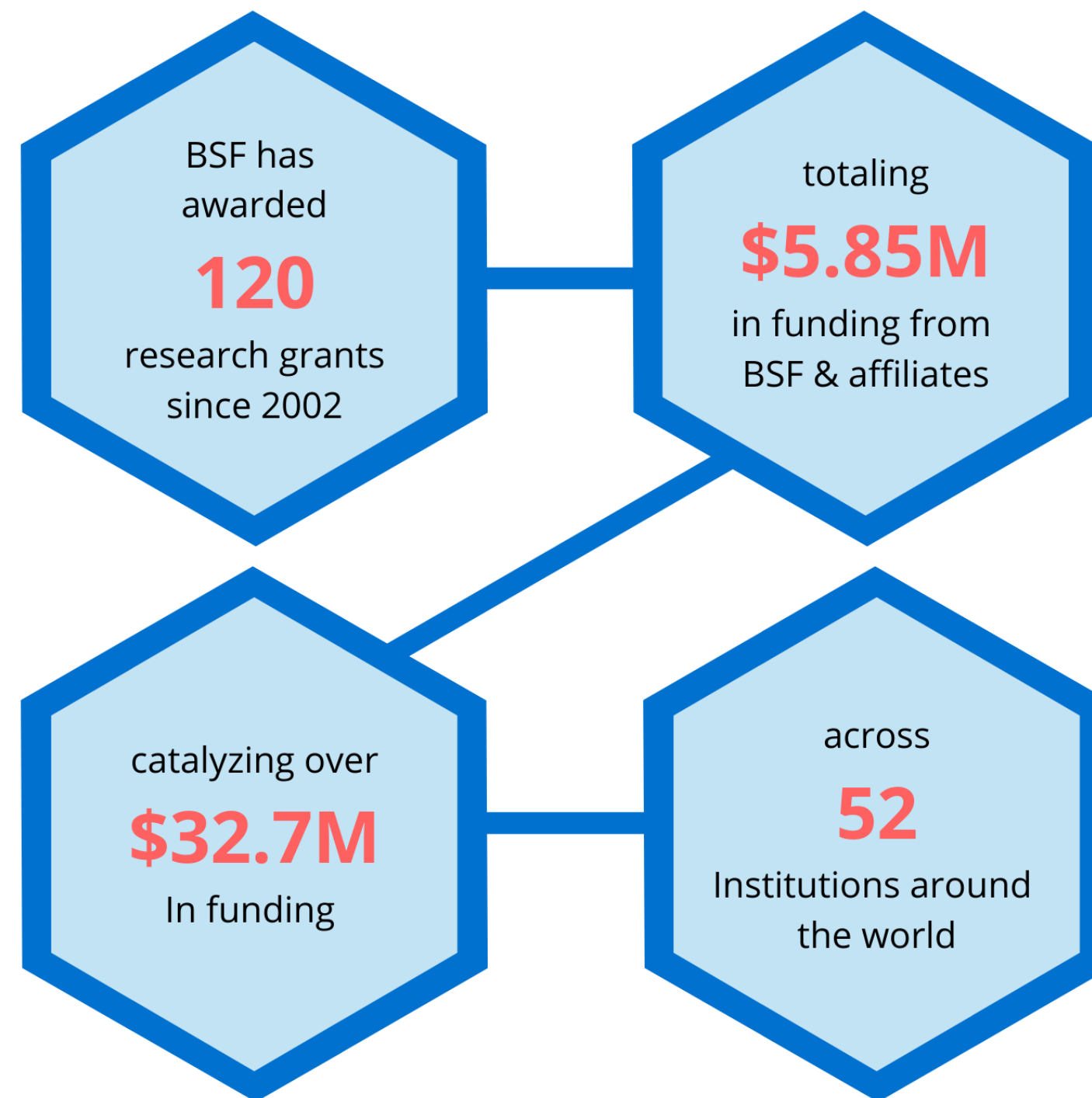
Never, Ever Give Up!

No matter the obstacles, we remain committed to our vision and the people we serve.

- Seize opportunities to progress our mission.
- Unite our community to advance our cause around the world.
- Bring together volunteers, families, and donors to grow our community and make it stronger!

Research & Development

In order to meet the needs and challenges faced by our community of affected individuals, **BSF's Research and Development Program** is driven to advance treatments, foster collaborative research, and offer scientific ambassadors to engage the partners essential to achieve our vision of a world in which Barth syndrome no longer causes suffering or loss of life



Grant Awards

Vetted by BSF's Scientific and Medical Advisory Board (SMAB), 2021 grantees' projects span novel areas of Barth basic science, drug repurposing and testing in the heart-specific *tafazzin* knockout mouse, and remotely conducted clinical research.

Activating Pyruvate Dehydrogenase Complex to Improve Barth Syndrome Cardiac Function

Development Award, \$100,000 over two years



Charles E. McCall, PhD
Wake Forest University
Health Sciences

Awarded to the multi-disciplinary team of Professors Charles McCall, Miriam Greenberg, Peter Stacpoole, and Boone Prentice, this Development Award will investigate the drug dichloroacetate's (DCA) impact on the heart-specific *tafazzin* knockout mouse. Involving animal research at Wake Forest University (McCall), cellular and cardioprotein expertise from Wayne State University (Greenberg), and clinical experience and research tools via the University of Florida (Stacpoole & Prentice), this mouse project asks whether DCA can be repurposed as an investigational drug and potential therapy for 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.

Cardiolipin synthesis and remodeling regulate mitochondrial metabolic plasticity and signaling function

Idea Award, \$50,000 over one year



Mauro Corrado, PhD
University of Cologne

Awarded to Dr. Mauro Corrado, this Idea Award builds upon novel findings that cardiolipin plays a key role in the development and function of T cells - immune cells that play a role in adaptive immunity. Utilizing mouse models, Dr. Corrado is focusing on the implications of impaired immune function and its impact on the health and function of mouse muscle cells. Given the immune issues faced by humans affected by Barth syndrome, this effort has the potential to provide a more holistic view of immune dysfunction in Barth syndrome.

This project's funding was made possible by the generous support of the Paula and Woody Varner Fund.

Surveying *TAFAZZIN* genetic interactions and mutational landscape in human cells

Idea Award, \$50,000 over one year



Jason Moffat, PhD
University of Toronto

Awarded to Professors Jason Moffat and Charles Boone of the University of Toronto, this Idea Award enables us to better understand the *TAFAZZIN* gene, in and out. Inwardly, Dr. Moffat proposes to connect changes in gene sequences to their functional consequences on protein function. Known as deep mutational scanning, this effort has the potential to expand our understanding about gene variants in our community. Outwardly, via a CRISPR-mediated genome-wide screen, Dr. Moffat proposes to identify genes that interact with *TAFAZZIN* and recorded gene variants. By increasing our understanding of *TAFAZZIN* interactions as well as gene variants and mutations' impact on tafazzin protein function, the research team seeks to identify insights into the variable manifestations, or phenotype, 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.

"What is Barth Tired?": A mixed methods approach to qualifying and quantifying fatigue in males with Barth syndrome

Idea Award, \$50,000 over one year

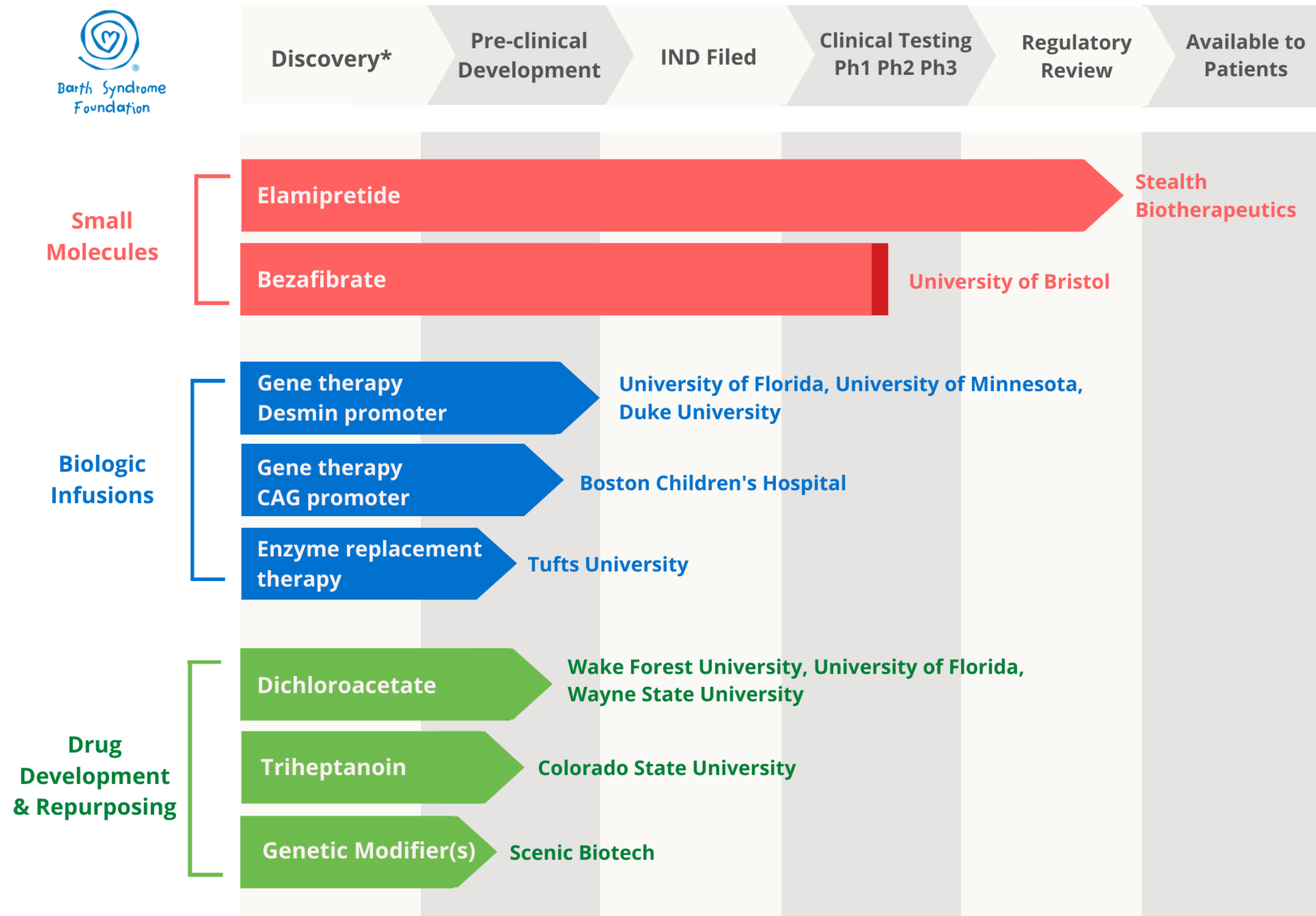


Stacey E. Reynolds, PhD
Virginia Commonwealth
University

Awarded to Associate Professor Stacey Reynolds and in collaboration with Assistant Professor Virginia W. Chu of Virginia Commonwealth University, this Idea Award aims to capture the fatigue experienced and voiced by our affected individuals. Dr. Reynolds's team will first conduct interviews with affected individuals, siblings, and parents to capture the impact of fatigue on daily living. Dr. Chu will then capture individuals' self-assessment of fatigue in real-time using a novel phone application and map those ratings onto activity data collected by wrist-worn watches worn by affected individuals. This mixed-methods approach aims to qualify and quantify fatigue in our community and is in direct response to the narratives shared during BSF's 2018 Patient Focused Drug Development meeting with the U.S. FDA.

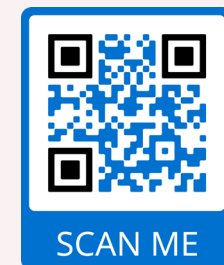
This project's funding was made possible by the generous support of the Will McCurdy Fund for Advancement in Therapies for Barth Syndrome.

Research & Development Pipeline



We won't stop until therapies are available to patients! Since our founding, BSF has maintained a relentless focus on getting a therapy into the clinic. Be it drug, gene, or enzyme, our goal is the same in delivering treatment options for our community. And in partnership with academia, government, industry, and our community of talented researchers, BSF remains committed to identifying and taking as many shots as possible on goal as possible.

MORE ABOUT BSF R&D:



www.barthsyndrome.org/research/

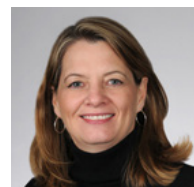
Publications

Over the last 20 years, our community of researchers, clinicians, affected individuals, and families have collaborated to outline the basic biology, pathophysiology, and symptomology of Barth syndrome. Now, in partnership with the **Journal of Inherited Metabolic Disease (JIMD)**, and selected by guest editors Fred Vaz, Hilary Vernon, and Ron Wanders, we are proud to share the news of **JIMD's Special Issue on Barth syndrome**. We appreciate the effort of all the contributing authors, guest editors, and of course JIMD's decision to shine a scientific light on the immense progress in the Barth syndrome field!

From the Authors



Barth Syndrome Foundation: From humble beginnings to becoming an integral partner "The multi-disciplinary and immensely qualified stature of the contributing authors in this issue are a demonstration of the medical and scientific professionals who have joined us as partners in our shared mission of saving lives through education, advances in treatment, and finding a cure for Barth syndrome." -Erik Lontok.



Clinical presentation and natural history of Barth syndrome: An overview "The Barth Syndrome community of patients and families continue to be highly invested in participating in long-term research and clinical studies. This allows clinicians and scientists to continue to enhance our knowledge and clinical care of patients with Barth Syndrome. Recognition and understanding of the natural history of this complex disease are important for anticipatory guidance and ongoing patient management as well as developing clinical endpoints to demonstrate the efficacy of new therapies." -Carolyn Taylor.



Current and future treatment approaches for Barth syndrome "Current treatment approaches in Barth syndrome include both expectant management, including regular monitoring for potential problems, as well as symptomatic management for ongoing issues. Ongoing research into novel, Barth syndrome-specific therapies includes two recently completed clinical trials to examine the effectiveness of bezafibrates and elamipretide and new potential therapeutic approaches on the horizon including gene and enzyme replacement therapy." -Hilary J. Vernon



An improved functional assay in blood spot to diagnose Barth syndrome using the monolysocardiolipin/cardioliipin ratio "We developed an improved biochemical test to screen for or confirm Barth syndrome in just a tiny bloodspot. It is easy to collect and send by regular mail. Before this innovation we needed to confirm in a venous blood sample, but with the new assay we can do all, just in one bloodspot." -Frédéric M. Vaz



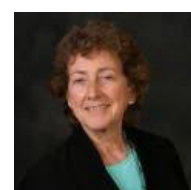
The lipid environment modulates cardiolipin and phospholipid constitution in wild type and tafazzin-deficient cells

"It is well known that Barth syndrome on a biochemical level primarily causes cardiolipin abnormalities. However, so far it is still debated if and how other lipids are disturbed as well. In cell culture experiments we could show that non-functioning tafazzin indeed alters lipids other than cardiolipins. Remarkably, we found that different lipid diets are able to either mask, but also promote these effects, enabling the development of improved model systems for evaluating novel therapeutic strategies." -Markus A. Keller



A simple mechanistic explanation for Barth syndrome and cardiolipin remodeling

"The paper provides evidence that cardiolipin supports protein crowding in mitochondrial membranes. This gives rise to a simple explanation for Barth syndrome. Patients are unable to meet high energy demands because they cannot concentrate the proteins required for respiratory energy metabolism." -Micahael Schlame



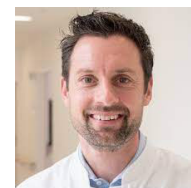
Cardiolipin function in the yeast *S. cerevisiae* and the lessons learned for Barth syndrome

"Studies using the yeast *S. cerevisiae* have provided valuable insights into the role of cardiolipin (CL) and CL remodeling in mitochondrial and cellular functions. Many functions of CL determined from the yeast studies have been validated in higher eukaryotic cells. These functions may be implicated in the pathology of BTBS and may also identify physiological modifiers that lead to the disparities in clinical presentation among BTBS patients." -Miriam L. Greenberg



Experimental models of Barth syndrome

"Efforts over the past decade, many supported by BSF, have created several experimental models of Barth syndrome. This JIMD article reviews these models and highlights their individual strengths. These models will enable discovery and testing of new therapies for Barth syndrome." -William T. Pu



Mechano-energetic aspects of Barth syndrome

"In patients with Barth syndrome, cardiolipin defects not only impair respiratory chain function, but also the uptake of calcium ions into mitochondria, which are required to activate the Krebs cycle when the heart needs more energy. This defect explains the inability of hearts of Barth syndrome patients to increase their output during exercise, and possibly also arrhythmias. Drugs that further aggravate such mechano-energetic uncoupling, such as cardiac glycosides, should therefore be avoided in patients with Barth syndrome as they contribute to heart failure." - Christoph Maack



Interplay between cardiolipin and plasmalogens in Barth syndrome

The identification of the interplay between the metabolisms of cardiolipin and plasmalogens opens new routes to be explored aiming to improve health outcomes in Barth syndrome." -José Carlos Bozelli jr

Family Services

Family Services works to champion a thoughtful, engaged, well-informed, inclusive community who are collectively invested in achieving the ultimate vision of saving lives and ending suffering caused by Barth syndrome.

Family Services Objectives

Advance collaboration among clinicians to improve health outcomes for people affected by Barth syndrome

Educate affected individuals and their families to help them understand the various symptoms of this complex disease and navigate its management

Grow and nurture a caring and supportive community to help empower affected individuals and their families

Integrate healthcare providers into BSF family programs and global community so that there is two-way benefit of increasing knowledge

Support individuals, families and physicians in their quest to obtain a diagnosis and throughout the Barth syndrome journey

Family Services: Patient-Centric Approach



Maintain a comprehensive library of Barth syndrome educational materials to support affected individuals and their families



Facilitate communications amongst the Barth community using an array of technologies including listserv, Facebook groups, virtual meetups, registry, surveys, and polls



Tailor programs and services to specific experiences of affected individuals, parents, siblings, care teams, and researchers



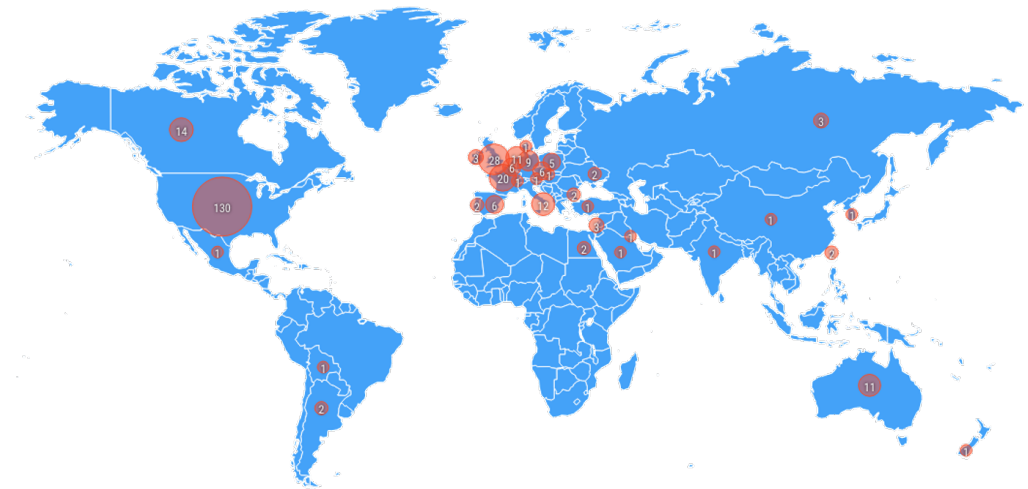
Support individuals and families through their Barth syndrome journey in areas of diagnosis, referrals, disability benefits, and healthcare decisions



Create frequent opportunities for knowledge and experience exchanges to inform crisis responses, care guidelines, and multimedia resources

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.

290 Individuals Living With Barth Syndrome Worldwide*



*As of December 2021

“Barth Syndrome Foundation works tirelessly towards giving practical help to our son’s increasingly debilitating disease. We are provided webinars with specialists and informed about medications and therapies and their international network provides us with great 24/7 help and advice. Barth Syndrome Foundation’s help and services get better year after year and are invaluable to us.”

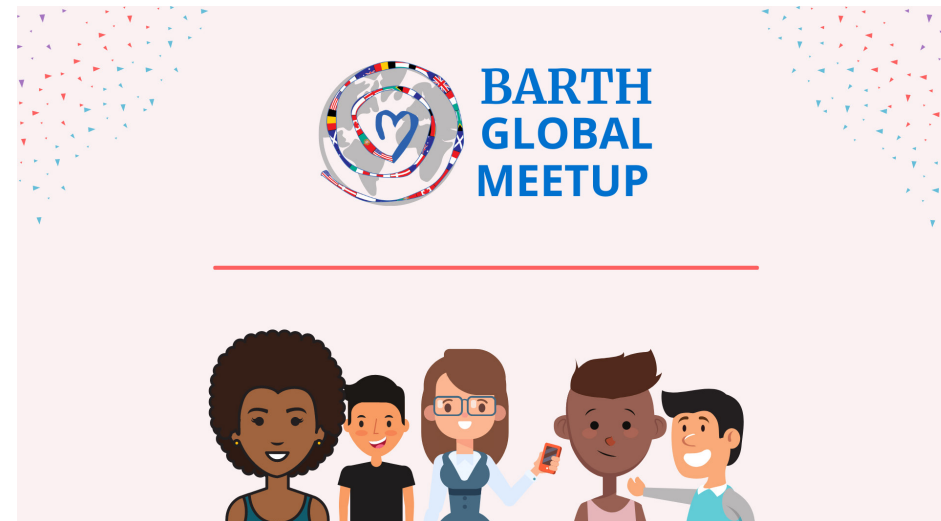
-Peter C

Barth Cares

Barth Cares was developed by BSF's Family Services volunteer working group to help build and maintain connectedness within the Barth syndrome community. The program

work involved developing and executing virtual gatherings of various types to meet the expressed desires of our community. Below are some of the highlights of the 2021 events.

Global Meetups



Our Global Meetups bring affected individuals, families, and volunteers together virtually in a relaxed atmosphere so they can openly chat with one another in their preferred language.

Year-end Celebration



In December 2021, we brought the community together for a virtual year-end celebration with games, performances, and even a gingerbread house competition!

Project Sunshine



Project Sunshine Teleplay provides youth (5 - 12 years old) with an opportunity to bond with others who are in a similar circumstance through fun. Project Sunshine's activities are designed to build relationships through cooperative and engaging play.

ECards



Ecards are designed as a solution for community members to show care and support from afar any time an individual is experiencing challenges or celebrating a milestone.

In Memory



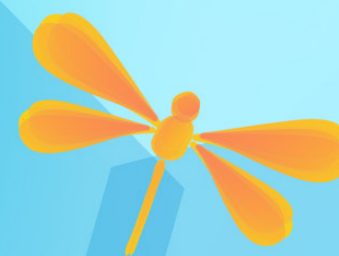
Bob Buckley, fondly referred to as “Uncle Bob” in the BSF community, passed away on August 30th, 2021. When Bob’s sister first contacted us after his diagnosis of Barth syndrome in 2005, he was the oldest person we knew of to be living with Barth syndrome. Bob was born and raised in Orange City, Iowa and began working on a neighbor’s farm when he was just a teenager. He had a talent for understanding how things worked with a unique appreciation for efficiency, something he had learned from a very early age.

When Bob was 53 years of age, he moved into the same assisted care facility where his father lived. After his father’s death, he moved to an assisted living facility a little closer to Orange City, Iowa, where he could ride his scooter into town to see his friends in the community. Bob participated in research when he could. For over five decades, Bob made his life an open book to share with anyone who would listen, helping to characterize what it was like to live with Barth syndrome.

Bob was well loved by his family and three sons. Due to his condition, Bob couldn’t participate in sports, but he had a love for mechanics. He passed his knowledge on to his sons by teaching them how to “tinker.” He didn’t have the strength or stamina to do many of the things fathers often do with their sons, but he taught them how to be good men.

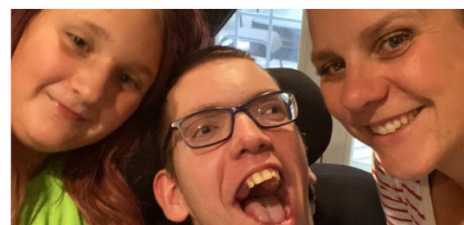
Bob once shared one of his most cherished memories with us. It was when his sons made a surprise visit. At the time, one of his sons was a Marine who traveled with Marine One. His sons showed up on Father’s Day of 2017 to take their dad to Des Moines, Iowa to see Marine One, the helicopter that transports the President of the United States. They had hoped to get Bob out for an overnight stay, but it was too much for Bob. It was even too much for him to get into the truck to make the trip. Nevertheless, these sons made it happen by lifting Bob up into the truck for one last road trip with dad.

Bob was a good friend, a man of great character. We will never forget you “Uncle Bob.”



I am forever grateful for BSF and the amount of resources and support they provide. They have given us so much knowledge and comfort that most physicians cannot. I don’t know where we would be today without these wonderful families and all the people involved getting us where we are today.

With love,
The Gattuso family



Advocacy

Advocacy is critical to develop partnerships that advance BSF's mission, educate healthcare providers, empower people with Barth syndrome, and develop support systems for individuals with Barth syndrome and their families

Advocacy Objectives

Partnerships Cultivate relationships with the greater rare disease community to increase opportunities for collaboration and change

Policy Inform the community of legislation and other systemic initiatives that directly impact the health and quality of life of those with Barth syndrome and amplify the Barth community voice

Awareness Increase awareness of Barth syndrome and its impacts on affected individuals and their families through education

Self-Advocacy Support individuals with Barth syndrome and their network as they advocate for their rights.

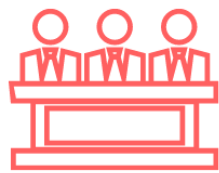
Advocacy In Action



July 2018: BSF hosted the first externally-led Patient Focused Drug Development meeting outside of the metro DC area.



March 2019: Submitted the Voice of the Patient Summary Report to the FDA.



March 2019: Held Barth syndrome listening session with US regulators at FDA headquarters in Maryland.



November 2020: Submitted to the FDA a community petition signed by more than 4200 individuals advocating for patient access to elamipretide, the first-ever potential therapy for Barth syndrome.



November 2020: Supported a key opinion letter signed by 26 clinical experts addressed to the FDA supporting the use of elamipretide in Barth syndrome.



March 2021: Convened a virtual listening session with the FDA to discuss the Barth syndrome community's tolerance of clinical benefit uncertainty for therapies.



Sept 2021: Published the StatNews opinion piece "Aduhelm backlash threatens to reverse progress in FDA's reviews of rare and ultra-rare disease drugs."



Oct 2021: Opened Annual EveryLife Foundation's Scientific Workshop focused on solutions to regulatory barriers in ultra-rare indications like Barth syndrome.

FDA Listening Session: Risk Tolerance

On March 3, 2021, the Barth Syndrome Foundation (BSF) held a Listening Session with 28 participants from various areas within the U.S. Food and Drug Administration (FDA) to discuss just this topic. In attendance were representatives from both the Center for Drug Evaluation and Research (CDER) Division of Cardiology & Nephrology and the Division of Rare Diseases & Medical Genetics, as well as representatives from the Center for Biologics Evaluation and Research (CBER). BSF and the global Barth syndrome (BTHS) community had requested a meeting, which the FDA welcomed, and then a carefully considered list of specific and highly thought-provoking questions for BTHS patients and caregivers to address was created. This provided first-hand accounts of whether and to what degree the BTHS- patient community would be willing to tolerate benefit uncertainty relative to that which is typically demonstrated in more common conditions for which multiple, large studies are able to be conducted.

Representatives of the Barth syndrome community conveyed the following messages:

- There is a dire unmet need for a treatment for our serious and life-threatening ultra-rare disease.
- We are an informed, thoughtful and engaged patient community who are willing to participate in clinical studies and trials.
- There is a high tolerance for uncertainty, including uncertainty of treatment benefit.
- Life itself is a basic human goal, but quality of life also is crucial. Reflecting just how challenging and life-constraining Barth syndrome can be, a number of patients and caregivers even stated that they would choose a better, somewhat shorter life to a much more difficult, longer one.
- We understand that not everything will work for everyone but there is an eagerness to have treatments to try, given the very bleak alternative.

Disclaimer: Discussions in FDA Rare Disease Listening Sessions are informal. All opinions, recommendations, and proposals are unofficial and nonbinding on FDA and all other participants. This report reflects the account of the perspectives of patients and caregivers who participated in the Barth Syndrome Listening Session with the FDA. To the extent possible, the terms used in this summary to describe specific manifestations of Barth syndrome, health effects and impacts, and treatment experiences, reflect those of the participants. This report is not meant to be representative of the views and experiences of the entire Barth syndrome patient population or any specific group of individuals or entities. There may be experiences that are not mentioned in this report.

MORE INFO:



SCAN ME

<https://qrco.de/FDAListens>

Rare Diseases On Capitol Hill



More than 600 advocates from 250 patient organizations came together virtually for Rare Disease Week on Capitol Hill that took place July 14-22, 2021. Shelley Bowen, BSF's Director of Family Services and Advocacy, was among those voices advocating for the Barth syndrome and other rare disease communities. "It's important to step up, show up and speak up with peer advocacy groups," Shelley said. "Alone, BTHS affects approximately 300 people in the world. But we amplify our voice when we work with other peer advocacy groups because the issues that are important to us collectively affect 30 million Americans with a rare disease. And that is a voice that cannot be ignored."

This year marked the 10th anniversary of this empowering and inspiring week of action coordinated by EveryLife Foundation. The robust schedule provided educational and networking opportunities for attendees, culminating in "Hill Day," where advocates encouraged congressional members to join the Rare Disease Congressional Caucus, cosponsor the Speeding Therapy Access Today Act of 2021, H.R. 1730/S. 670, cosponsor the Newborn Screening Saves Lives Reauthorization Act, H.R. 482/S. 350, cosponsor the S. 373 the Better Empowerment Now to Enhance Framework and Improve Treatments (BENEFIT) Act, and cosponsor the Access to Genetic Counselor Services Act H.R. 2144 / S. 1450. The

Diversity Roundtable was another important session during the week. Patient advocates, industry leaders, and community stakeholders participated in inclusive roundtable discussions about the barriers to care for underserved rare disease communities and the policy solutions that can make a difference. Breakout sessions focused on topics including access, representation, clinical trials and therapy development, and newborn screening and diagnostics.

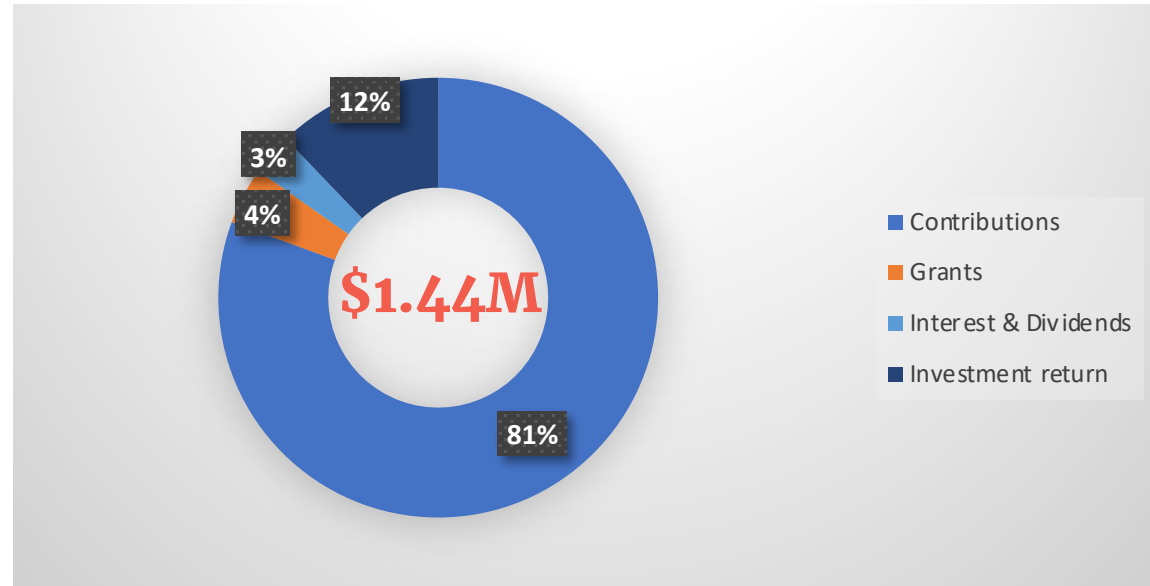
"This organization works diligently to help each and every Barth syndrome patient and their families. Wonderful, caring organization."

-June S.

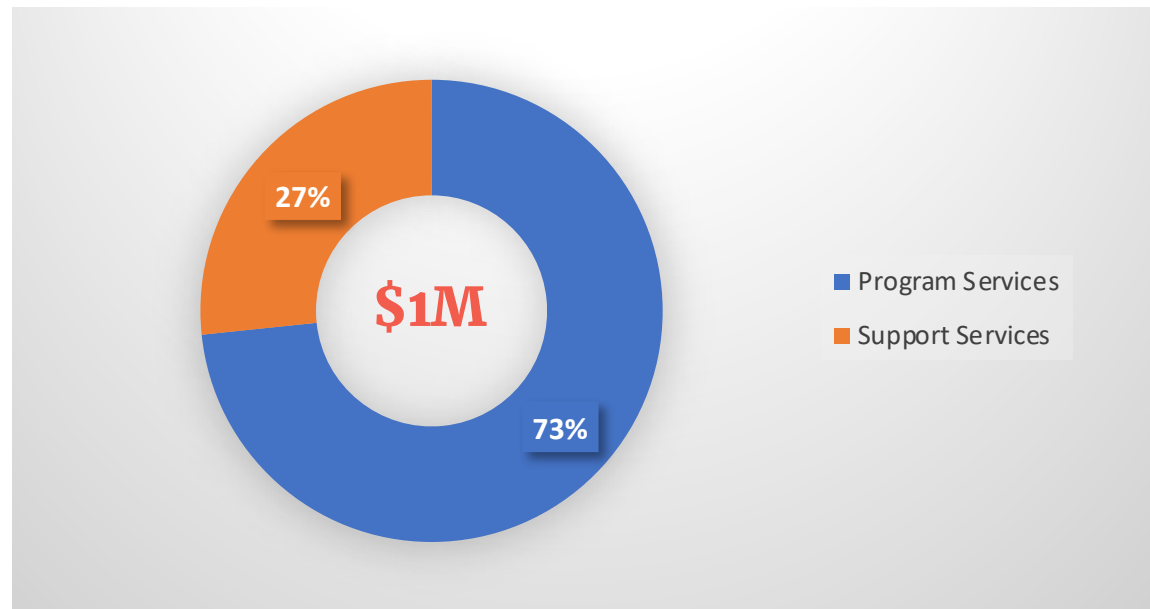
Financials

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.

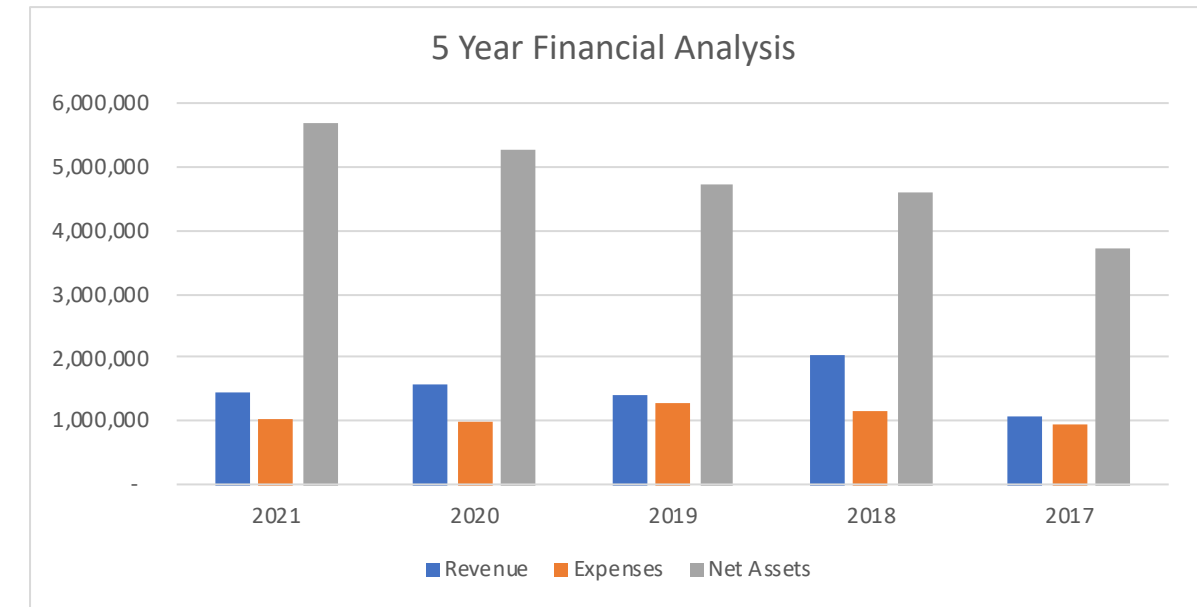
2021 Revenue



2021 Expenses



5 Year Trend



2021 Program Services Breakdown

| | |
|-------------------------------|-----------|
| Research Grants | \$204,594 |
| Science & Medicine | \$193,353 |
| Communications & Awareness | \$132,154 |
| Family Services | \$96,953 |
| Advocacy | \$95,538 |
| Barth Registry and Repository | \$18,816 |

PARTNERING WITH PURPOSE

We learned during the 2018 Patient-focused Drug Development (PFDD) meeting of the universal and debilitating impact of fatigue on our affected individuals. To directly address this issue, in 2021 BSF awarded Dr. Stacey Reynolds (VCU) a grant to better understand what it means to be “Barth Tired.” With one arm aiming to understand the context or qualitative aspects of the fatigue associated with Barth syndrome, here we aim to highlight the BSF-industry-academia partnership critical to advancing the quantitative arm of the study.



Dr. Reynolds’ past experience with GT9X Accelerometer in studying the sleep and activity patterns of affected individuals indicated the high probability of success conducting a fully-remote research effort. Beginning in winter 2019, BSF reached out to the GT9X maker ActiGraph LLC for potential project support for the Barth Tired study – culminating in an in-kind contribution of 25 devices as well as

software licenses for the effort. Collaborations where we can leverage the expertise of a highly engaged researcher, partnered with an industry member, is a prime example of the ways BSF is advancing our mission beyond research funding. With the launch of the “Barth Tired” study, we are developing a Barth syndrome-specific clinical measure while also deploying a model for collaboration with future and potential industry partners – because we know it takes a village to address the key challenges faced and voiced by our affected individuals. Please visit our website to learn more or participate in the “Barth Tired” study.



2021 also saw BSF’s first ever co-funding partnership with the American Heart Association (AHA). Marking a strategic investment by BSF to broaden our research impact, we joined forces with AHA to accelerate progress through science and education. Awarded to Dr. Nanami Senoo in Dr. Steve Claypool’s lab (JHU), the two-year postdoctoral fellowship provides research support to explore the relationship of cardiolipin and the nucleotide transporter ANT1 in

cardiac models. With a shared research interest in cardiomyopathy and cardiolipin, it is our goal that this effort with AHA advances Barth syndrome science, while also serving as a collaborative template for other potential non-profit partners with shared clinical indications and research interests. Importantly, this program also provides a funding opportunity for trainees at the pre- and post-doctoral career stage.

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.

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