Barth Syndrome Foundation®

# 2025 ANNUAL REPORT

In 2025, the Barth Syndrome Foundation celebrated its 25th year with the approval of FORZINITY™ (elamipretide), the first-ever FDA treatment for Barth syndrome and for any mitochondrial disease in the United States. 25 is an age that many members of our community never see, and this milestone brings hope we have never had before — both to our community, and to the broader rare disease community.

It can be easy to see the end-result and forget the journey. There were years of hard work, smaller celebrations, and setbacks sitting under the success that was the new drug approval. Obstacles and uncertainty were our steadfast companions every step of the way — and they remain with us still post-approval, as we push for label expansion (in terms of both age and geography) and a successful confirmatory Phase IV trial outside of the U.S. to secure a full traditional FDA approval.

In this moment, we celebrate with renewed resolve. We find inspiration in each other every day, and together with our affiliates and our global community, we forge ahead. We do so not only for everyone who could benefit from FORZINITY but also for everyone in the Barth and rare disease communities who anxiously await treatments that will enable them to live their best lives.

We are proud of who this community is – steady, persistent beyond all measure, and grounded firmly in the science and research that is improving quality of life for individuals and families affected by Barth syndrome. We are excited for what's next as we seek more treatments and a brighter future for all impacted by this disease.

Thank you for being here with us in this moment of celebration, and most importantly in every moment behind us and ahead of us.

With gratitude,

Emily & Kate

Chief Executive Officer

Board Chair

# About the Barth Syndrome Foundation

**For over two decades, the Barth Syndrome Foundation has raised awareness of Barth syndrome, funded science and research to better understand and treat it, and made sure no family faces this disease alone.**

**In 2025, that persistence reached a turning point: the FDA granted accelerated approval to FORZINITY™, the first-ever treatment for Barth syndrome. This milestone is proof of what this community can accomplish together.**

## OUR MISSION

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

## OUR VISION

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

## OUR VALUES

- We ensure that BSF stands for: Credibility, Integrity, Community, Professionalism, and Compassion.
- We are respectful of the time and talents we are offered and are good stewards of the resources we are given.
- We value collaboration and constantly seek to improve by listening to and learning from others.
- We encourage a broad range of perspectives within our Board and committees, and strive to represent the needs of our community in our program areas.
- We recognize the unique and personal challenges of every person and family affected by Barth syndrome and pledge to them our commitment, compassion and respect.
- When representing BSF we place the interests of all those affected by Barth syndrome above the interest of any one individual.
- We will never ever give up until a cure and effective treatments have been made available to all individuals affected by Barth syndrome!

**There are about 150 individuals known to be living with Barth syndrome in the United States and about 300 globally, making it one of the rarest diseases on earth.**

*But small numbers doesn't mean small impact. We are leading the way in therapies and advocacy for rare diseases for our communities and others across the globe.*

In collaboration with our global affiliates in Canada, France, Italy, and the UK, the Barth Syndrome Foundation (BSF) exists to change the outcome for every person affected by Barth syndrome, wherever they live.

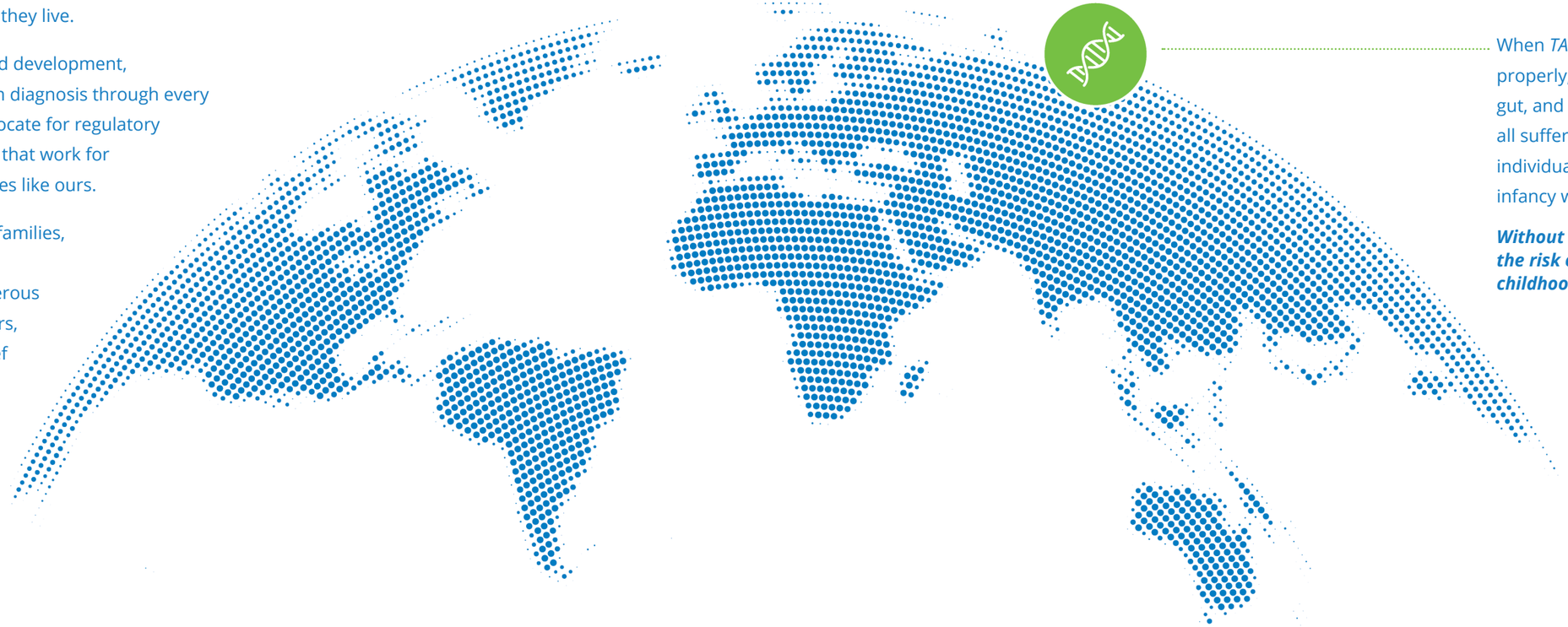
We fund research and development, support families from diagnosis through every stage of life, and advocate for regulatory and policy processes that work for ultra-rare communities like ours.

We are dedicated to families, driven by science, powered by our generous donors and volunteers, and built on the belief that every person with Barth deserves a long and full life.

XY

# What Is Barth Syndrome?

Barth syndrome is a rare, life-threatening genetic condition. It primarily affects boys and men from birth. It is caused by a change or mutation in the *TAFAZZIN* gene that produces a protein which the body needs to make a fat called cardiolipin inside the mitochondria — the tiny structures in nearly every cell that generate energy.



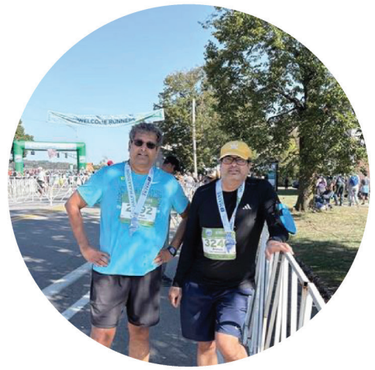
When *TAFAZZIN* doesn't work properly, the heart, muscles, gut, and immune system all suffer. Many affected individuals are diagnosed in infancy with heart failure.

***Without treatment, the risk of death in early childhood is high.***

# Community

$115,000+ RAISED
**GIVING TUESDAY 2025**
*45+ fundraisers*

$101,000+ RAISED
**HOCKEY WITH A HEART**
*March 22 | USB Arena*
*Mason lit the lighthouse.*



$5,000+ RAISED
**ATHLETES IN ACTION**
*In addition to Dr. Anyonya Guntur's Maine Half Marathon Fundraiser, Dr. Guntur has shared his research with our community through Research Roundtables as well.*

$30,000+ RAISED
**BEACONS FOR DEACONS**

$320,000+ RAISED
**HAPPY HEART PARTY**
*September 27 | JBL Ranch, Briones, CA*
*Over $1 million raised since inception.*

## Showing Up for Each Other

**FAMILIES ARE THE HEART OF OUR WORK.**

**Alongside advocacy and research, we're committed to supporting our community every day — picking up the phone at the right moment, sharing a resource to help a family navigate a school meeting, bringing together the people who just get it.**

### TOOLS FOR SCHOOL

Starting a new school year is complicated when your child has Barth syndrome. In 2025, BSF expanded our Tools for School resource library to help families and educators navigate that complexity together — covering educational protections, developmental and physical considerations, and practical guidance for building a strong school team.

Every student with Barth syndrome deserves an informed team behind them.

### ADULT MEN'S COMMUNITY CALLS

Barth syndrome follows people into adulthood and so does the support that BSF provides. Our new monthly call series for adult men with Barth syndrome offered a space in 2025 to talk honestly about parenting, relationships, work, and the everyday realities of living with a rare disease — from anywhere in the world.

### BEREAVEMENT SUPPORT

Our community lost seven children under the age of 10 in 2025. No milestone, no approval, no good news erases that or eases the pain. The affected families carry grief that is real and lasting, and BSF walks alongside them through it — as faithfully as we walk alongside families through diagnosis, treatment, and advocacy. We honor every member of this community we have lost. We always will.

### INSURANCE & ACCESS NAVIGATION

FORZINITY™ (elamipretide) approval brought a new set of urgent and unexplored questions about coverage, transitions from the Expanded Access Program, and what to do when insurance says no. We've been hard at work sharing information as it is made available and supporting families as we navigate this new landscape together.

**Together, we raised over $2M in 2025 to support family services, research funding, and community connection.**

# Advocacy

**In September 2025, the United States Food and Drug Administration (FDA) granted accelerated approval to FORZINITY™ (elamipretide), the first approved treatment for Barth syndrome and the first treatment for a mitochondrial disease ever!**

*The approval would not have been possible without this community's advocacy.*

## The Year Began with Uncertainty

At the start of 2025, nearly two years had passed since the developer of FORZINITY, Stealth BioTherapeutics, first submitted the drug for FDA review. Regulatory review — a process generally built for diseases with large populations — had been delayed, restarted, and complicated at every turn. Despite a foundation of rigorous science and positive data, regulators wanted to see studies with more patients — an impossible demand for our tiny community.

Decision deadlines in January and in April came and went without an answer from the agency. In May, the agency sent a complete response letter: they would not approve the drug. Stealth requested reconsideration, which the FDA refused and instead required a third costly and extensive resubmission. Stealth completed the request although they could no longer guarantee the company's funding for much longer. Even the patients who had access to the drug through the Expanded Access Program were at risk of losing it within a few short months.

But we knew the science was strong and that families wanted access. We refused to accept that this was the end of the story, and so did Stealth.

## Our Community Showed Up

Nearly 3,000 advocates sent more than 5,400 letters to Congress and the FDA. BSF volunteers contacted 363 Congressional offices, interacting with each at least four times and resulting in 198 Congressional meetings. Barth syndrome appeared in ABC7 Chicago, NBC News, and local outlets across the country. Physicians published their expert opinions on the process and the drug.

On September 19, 2025, the FDA granted accelerated approval of elamipretide for individuals with Barth syndrome weighing at least 30 kg (approximately 66 lbs). It is the first approved treatment for Barth syndrome and the first FDA-approved mitochondria-targeting therapy. The approval recognized the strong scientific foundation, the positive data, and the advocacy of this community and our rare-disease partners.

**2025**

**JANUARY**

**FORZINITY Decision Deadline**

*No response from the FDA.*

**APRIL**

**FORZINITY Decision Deadline**

*No response from the FDA.*

**MAY**

**FORZINITY Complete Response Letter**

*The FDA issues a rejection letter for FORZINITY, requesting more data — a difficult task given the rarity of Barth syndrome. The manufacturer, Stealth BioTherapeutics, requested reconsideration, which the FDA refused and instead required a resubmission.*

**JUNE - AUGUST**

**Advocacy Efforts**

*Based on evidence they had witnessed or heard about, nearly 3,000 advocates sent more than 5,400 letters to Congress and the FDA. BSF volunteers contacted 363 Congressional offices, interacting with each at least four times and resulting in 198 Congressional meetings. Barth syndrome appeared in news outlets across the country. Physicians published their expert opinions on the process and the drug and >80 signed on to a letter to FDA.*

**SEPTEMBER**

**Accelerated Approval**

*The FDA granted accelerated approval of elamipretide for individuals with Barth syndrome weighing at least 30 kg (approximately 66 lbs).*


## A Milestone, Not a Finish Line

And yet, this community knows better than most that, sometimes, a victory is just the first step.

As of March 2026, FORZINITY is only available to individuals weighing at least 66 pounds, which means children under that threshold and including many of the most medically fragile, remain without traditional access. The approval is incomplete: Stealth must satisfy the FDA requirement of a Phase 4 confirmatory trial with yet more patients. For families outside the United States, approval here does not guarantee access there.

# What Comes Next

**We're proud of what our community has achieved.**
**We're clear-eyed about what remains.**
***We have work to do.***

*In 2026, BSF's advocacy work will focus on:*

- Expanding the drug label to cover individuals under 66 pounds
- Supporting insurance access and helping families address coverage challenge for families in the U.S.
- Building the regulatory pathway for the next generation of Barth and other rare disease therapies, so future treatments are not prone to so much uncertainty
- Navigating post-approval commitments and the required confirmatory trial
- Coordinating with international affiliates and global partners as elamipretide moves toward regulatory approval in other countries



# By the Numbers

**30+**
***advocates from 17 states traveled to Washington, D.C. for Rare Disease Week***

**70+**
***letters sent to the FDA Commissioner's office***

**1**
***historic meeting with the FDA Commissioner***


**1st**
***FDA-approved treatment for Barth syndrome***

**16** ***members of Congress recognized as Champions of Progress***

Senator Mark Kelly (AZ)
Senator Roger Wicker (MS)
Representative Jake Auchincloss (MA-04)
Representative Gus Bilirakis (FL-12)
Representative Buddy Carter (GA-01)
Representative Sharice Davids (KS-03)
Representative Mike Flood (NE-01)
Representative Michael Guest (MS-03)
Representative Morgan McGarvey (KY-03)
Representative Jim McGovern (MA-02)
Representative Doris Matsui (CA-06)
Representative Ralph Norman (SC-05)
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Representative William Timmons (SC-04)
Representative Lori Trahan (MA-03)
Representative Joe Wilson (SC-02)

# Research

## Families Deserve an Array of Safe and Effective Therapies

At the 2025 National Organization for Rare Disorders Summit, our Director of Family Services and Advocacy, Shelley Bowen, put it plainly to a room full of rare disease leaders: families aren't waiting for a seat at the table to participate in Barth research and decisions. The table belongs to us. Families are experts, not guests. This is the foundation of our research work.

BSF funds research because we believe that families and science are stronger together. We provide seed grants to early-career and established investigators around the world, providing them with early investments that help generate the preliminary data needed to attract larger funding. Since 2003, BSF has sponsored $7.5 million in research funding, which has catalyzed more than $43 million in follow-on Barth syndrome funding by others. In 2025, 47 articles were published on Barth syndrome with a good portion funded, at least in part, by BSF. These publications are significant: one collaboration between a BSF-funded researcher and a biotech led to a seminal discovery that will have great implications for the therapeutic landscape. You can read more about that below.

### A Published Breakthrough

In September 2025, a collaboration between several Barth research teams resulted in the publication of a landmark study in *Nature*, one of the most respected scientific journals in the world. The research was funded in part by a grant from BSF in 2021 to Dr. Jason Moffat.

Here is what they found, in plain terms. Barth syndrome is caused by a mutation in the gene that makes a protein called TAFAZZIN. In healthy cells, TAFAZZIN performs a critical job: it converts an immature fat called monolysocardiolipin (MLCL) into a mature form called cardiolipin. Mitochondria in cells, especially heart cells, need cardiolipin to produce energy. Yet in Barth syndrome, TAFAZZIN can't do its job. MLCL piles up. Mitochondria cannot produce enough energy, and cells struggle to function. This leads to the many debilitating symptoms seen in Barth patients.

While we knew that TAFAZZIN converts MLCL to cardiolipin, we did not know the identity of the protein that converts nascent (immature) cardiolipin into MLCL.

**In the 2025 *Nature* study, researchers identified the protein ABHD18 as the key player.** When ABHD18 was removed from cells in mice that also lacked TAFAZZIN, the harmful buildup of MLCL was prevented. Cell function was largely restored to normal. Mice without ABHD18 and TAFAZZIN avoided the cardiac problems typically seen in Barth syndrome entirely. Importantly, this work was also confirmed independently by a group of researchers led by Drs. Mindong Ren, Michael Schlame and Miriam Greenberg, all members of the Barth Syndrome Foundation Scientific and Medical Advisory Board.

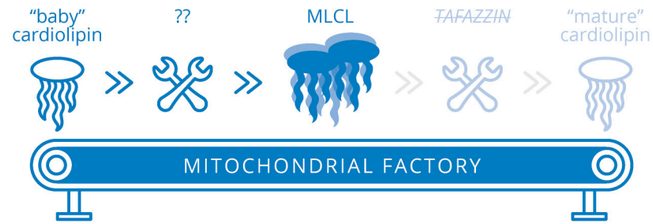
These findings are important because they open an entirely new avenue for treatment. Existing approaches aim to replace or repair TAFAZZIN directly. Now, researchers can target a second, independent protein — one that can potentially be affected by drugs.

"This discovery was made possible through the support of the Barth syndrome community, and we're looking forward to the next stage of research and turning this target into treatment. This is the long game of rare disease research, and it's working," Dr. Marjoram says.

> ***Identifying the protein responsible for making MLCL in humans has been one of the holy grails of Barth syndrome research.***
>
> **DR. LINDSAY MARJORAM**
> *BSF's Chief Scientific Officer*

## Barth syndrome

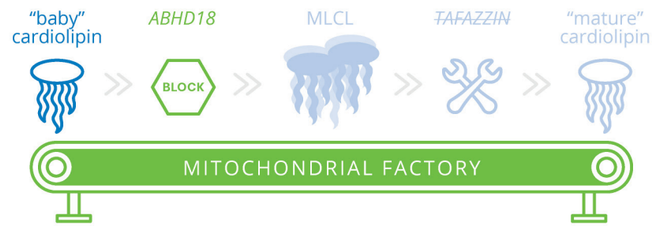
*The TAFAZZIN gene has a change or mutation that prevents it from making a protein that can work on the cell's factory line.*




## New! discovery

*The 'factory worker' that converts baby cardiolipin to MLCL has been identified.*

In mice, blocking ABHD18 when TAFAZZIN doesn't work can reverse the symptoms of Barth syndrome.




***To this end, Barth Syndrome Foundation has already funded two additional grants aimed at identifying ABHD18-inhibiting drugs.***

# Grant Recipients

**BSF awarded grants to three institutions in 2025, with generous support from our international affiliates.** *Here are the institutions and their principal investigators:*

1

AMSTERDAM, NETHERLANDS

### SCENIC BIOTECH

*$100,000 | 1-year award | Vincent Blomen, PhD*

Dr. Blomen is developing a class of drug called an antisense oligonucleotide (ASO) — a molecule designed to instruct cells to stop producing ABHD18. His work will test whether an ASO can reduce ABHD18 levels and reverse the symptoms of Barth syndrome in mouse models.

*Co-funded with Association Syndrome de Barth France.*

2

TORONTO, CANADA

### THE HOSPITAL FOR SICK CHILDREN

*$70,000 | 2-year award | Jason Moffat, PhD*

Dr. Moffat is evaluating small molecule inhibitors — drugs designed to block ABHD18's activity — as a potential therapy for Barth syndrome. His work tests whether these molecules can effectively suppress ABHD18 and, in doing so, correct the underlying cellular dysfunction.

*Co-funded by Barth Syndrome Foundation of Canada, Barth Syndrome UK, and Barth Italia.*

3

INDIANAPOLIS, UNITED STATES

### INDIANA UNIVERSITY

*$80,000 | 2-year award | Simon J. Conway, PhD*

Dr. Conway is studying a novel mouse model of Barth syndrome that carries a mutation found in an actual affected individual. This model allows exploration of TAFAZZIN's functions beyond its primary enzymatic role, and Dr. Conway's work focuses on how the mutation influences the p53 pathway, potentially uncovering new signaling targets for future therapies.

BOSTON, USA

### STRATEGIC INITIATIVE PROGRAM

*ONGOING | Year 3 | William Pu, MD*

One promising treatment approach for Barth syndrome is gene addition therapy, which uses a modified virus (called an AAV vector) to safely deliver a healthy copy of the *TAFAZZIN* gene directly into cells. In mouse studies, this approach has successfully prevented and even reversed heart and muscle weakness. The Barth Syndrome Foundation is currently funding research to optimize all components of the AAV vector to best reach heart and muscle cells.

*This is a multi-year grant and in its third year, supported the important in-life testing to ensure that the optimized version of the viral vector is effective and safe.*



## *Looking Ahead*

JULY 19-25 | BONITA SPRINGS, FL

### 2026 Barth Syndrome International Scientific Medical and Family Conference

*This event will bring together researchers, clinicians, families, and industry partners to advance this work together. Research is a collaboration. It always has been.*

LEARN MORE

***BSF's annual grant cycle continues to attract innovative proposals addressing the basic, translational, and clinical research challenges of Barth syndrome.***

***For early-career researchers, our partnership with the American Heart association provides the opportunity for funding through their Predoctoral and Postdoctoral funding programs.***

# Registry & Repository Benefits

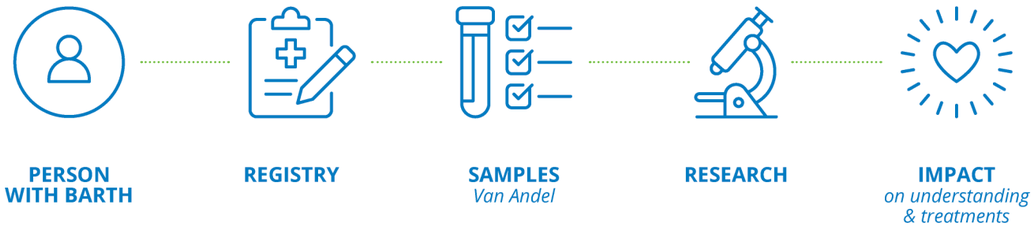
## The Barth Syndrome Registry and Repository (BRR) is a secure database that collects information about people living with Barth syndrome.

It brings together patient-reported health information, electronic medical records, genetic test results, and biological samples from affected individuals and families around the world — all in one place, dedicated to advancing our understanding of Barth syndrome.

When affected families participate in the Barth Syndrome Registry and Repository, they are helping drive the science forward for every person affected by Barth syndrome.

If an affected individual is interested in contributing, they can enroll via the Barth Syndrome Registry and Repository website where they will consent and provide their information.

To protect participants' privacy when data is shared with researchers, a de-identified linking code called a Global Unique Identifier (GUID) will be assigned to each person. Survey and clinical data are housed within the patient registry (Matrix) while donated biological samples are housed in BSF's biorepository at Van Andel Institute.




*This project has been made possible in part by a grant (Cycle 3 Rare As One, now known as Biohub) from the Chan Zuckerberg Initiative DAF, an advised fund of Silicon Valley Community Foundation.*

***The BRR makes a real-world impact: two papers were published in the past two years based on BSF registry data.***



We have two exciting updates about BSF's registry and biorepository (the BRR):

### 1 All specimens collected are now housed at BSF's very own biorepository at the Van Andel Research Institute

BSF now has full autonomy over its samples and has a live inventory that can attract research.

Van Andel offers laboratory services should BSF need sample processing and serves as a lab extension when its needed.

Be on the lookout for the official launch of the registry in 2026 at BSF's conference, where blood specimens will also be collected for the biorepository.

LEARN MORE

ENROLL HERE

### 2 The Barth Syndrome Registry has migrated to a new, modern platform powered by Matrix with the following features: (BRR 3.0)

**Improved Patient Experience**
*Patient-reported outcome data is now collected in bite-size surveys, and patients can stop mid-survey without losing progress.*

**Electronic Medical Record Integration for U.S. Enrollees**
*This feature allows medications, test results, and reports from multiple doctors' visits and hospitals to seamlessly upload to the registry and strengthen the data collected.*

**Global Connectivity**
*The registry platform interface will be available in several languages.*

**Additional Functionality**
*Enrollees can also take advantage of helpful features like a diary, symptom log, and a sharing center to easily communicate with doctors.*

# 2025 Donors

## $25,000+

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Thomas Rubin & Nina Russell
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Marc & Tracy Sernel

## $10,000+

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Stealth BioTherapeutics Inc.
Dr. Jerry W. Wilkins

## $5,000+

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## $1,000+

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