Annual Report 2024

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 the Barth Syndrome Foundation 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 the foundation 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!

Working together, we are making a difference in the lives of people with Barth syndrome and their families. One day there will be a cure; we hope you will help us make that day come sooner.

DEAR BARTH FAMILIES, FRIENDS, & PARNTERS,

2024 was a year of historic milestones for the Barth syndrome community. After years of unwavering advocacy and persistence, we witnessed significant progress in our mission to advance treatments for Barth syndrome. In October, the FDA's Cardiovascular and Renal Drugs Advisory Committee voted 10-6 in favor of elamipretide's effectiveness.

As we await the final decision from FDA, we will continue to face every hurdle in our path with determination, energy, and a clear collective voice. Our community is extraordinary in our ability to unite, persevere, and drive change.

While advocacy took center stage, 2024 was also a year of joyful reunion. After a six-year pandemic hiatus in order to keep our immune-compromised community safe, we brought our global community together again for the International Barth Conference, welcoming 356 attendees to share knowledge, participate in groundbreaking research, and strengthen the bonds that make our community so resilient. The conference featured our first-ever Continuing Medical Education (CME) seminar and facilitated over 200 research appointments, advancing our understanding of Barth syndrome and potential treatments.

Research breakthroughs continued to illuminate new possibilities for treatment. From leveraging learnings from our patient registry to advances in gene therapy approaches, our commitment to funding innovative science is yielding promising results. Along with our international affiliates and research partners, we're fostering collaboration that accelerates progress toward our shared goals.

As we look ahead, whatever the decision by the FDA, we remain steadfast in our mission to improve the lives of those affected by Barth syndrome. The dedication of our donors, the engagement and resilience of our families, and the brilliance of our researchers continue to drive us forward.

We extend our deepest gratitude to everyone who contributed to our 2024 achievements. We invite you to use the QR code to continue to financially support our efforts in the years to come.

Every single dollar helps us to conduct research, support patients and advocate for change that advances our mission.

With hope and determination,

Emily Milligan
Executive Director

Kate McCurdy
Board Chair

OUR COMMUNITY

WITH EVERY NOTE, A STEP FORWARD

At this year's conference, families affected by Barth syndrome wrote messages on sticky notes — simple but powerful reflections on what it means to belong to this community. These handwritten words became something more than conference mementos. They became markers of courage, connection, and determination.

As we reflect on the progress made this year, we're carrying those messages with us — literally and symbolically — throughout this annual report. Each sticky note is a voice. Each voice is part of a movement. Together, they map out our journey toward **#BarthProgress**.

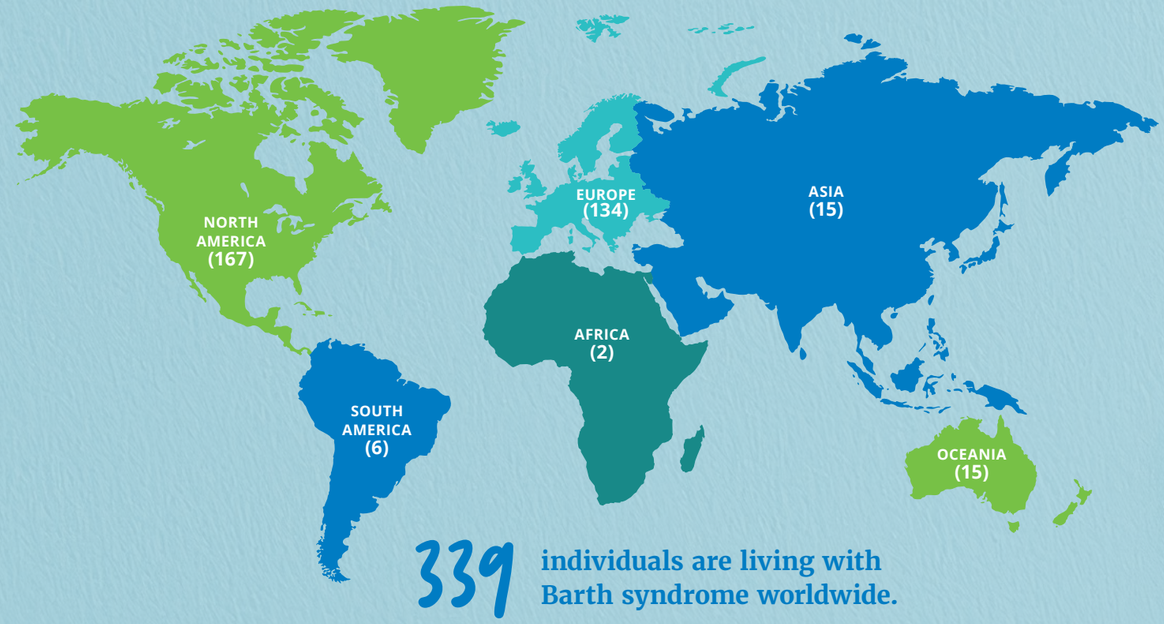
When Barth syndrome enters a family's life, it transforms everything.

The journey begins with a diagnosis that often comes after a long search for answers, bringing with it a mix of relief and uncertainty. Questions multiply, medical terminology becomes a second language, and families find themselves navigating a path few others understand.

For over two decades, the Barth Syndrome Foundation has stood alongside our families, providing the information, support, and resources needed to meet the daily challenges of living with this rare genetic disorder. Our community spans the globe—reaching families in the United States and more than 30 additional countries—supporting people through every stage from suspected diagnosis to bereavement.

What makes our foundation unique is not just the services we provide, but the connections we foster. Through our support networks, families discover they are not alone. They meet others who truly understand their challenges and can offer both practical advice and emotional support that only comes from shared experience.

In this annual report, you'll learn of the remarkable work we are doing to help our community who, despite facing extraordinary challenges, demonstrate remarkable strength and compassion for others walking similar paths.



339 individuals are living with Barth syndrome worldwide.

GLOBAL STATISTICS

By Continent & Country

AFRICA	ASIA		EUROPE			NORTH AMERICA	SOUTH AMERICA	OCEANIA
Egypt (2)	China (2)	Israel (4)	Austria (1)	Germany (13)	Slovakia (1)	Canada (16)	Argentina (2)	Australia (14)
	Taiwan (2)	Korea (1)	Belgium (6)	Ireland (4)	Scotland (3)	Mexico (1)	Bolivia (1)	New Zealand (1)
	Vietnam (1)	Kuwait (1)	Bulgaria (2)	Italy (16)	Spain (6)	USA (150)	Brazil (3)	
	India (2)	Saudi Arabia (1)	Czechia (6)	Netherlands (11)	Switzerland (1)			
	Japan (1)		Denmark (1)	Poland (7)	Turkey (2)			
			England (26)	Portugal (2)	Ukraine (1)			
			France (19)	Russia (4)	Wales (2)			

Barth Syndrome Foundation international affiliate

SUPPORTING FAMILIES

Connecting our Community

In 2024, the Barth Syndrome Foundation strengthened our global community through meaningful connections, both in-person and virtually, creating spaces where families could share experiences, learn, and support one another.

2024 INTERNATIONAL CONFERENCE

356 attendees from more than 10 countries

115 sessions on clinical care and family support, scientific and medical research, advocacy and community engagement, and wellness and inclusiveness

235 contributing to the understanding of Barth syndrome

FOURTH FRIDAY ROUNDTABLES

Throughout the year, our **Fourth Friday Roundtables** provided regular opportunities for our community members to engage directly with subject matter experts of topics ranging from mitochondrial dysfunction to feeding challenges. Presentations utilized Wordly for translation services and were saved to BSF's website, ensuring global accessibility.

Snapshot of Resources Added in 2024:

Mito 101: an introductory crash course on what mitochondria are

Feed the Baby: Author and lactation consultant Victoria Facelli provided an interactive demonstration of how to feed babies with low muscle tone

RARE DISEASE WEEK

Our advocacy efforts during **Rare Disease Week** strengthened connections beyond policy discussions, fostering solidarity among families sharing similar journeys.

21 advocates from 16 states

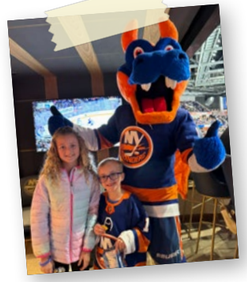
109 Congressional Meetings

Whether through our expanding social media presence during awareness days, regional gatherings, or virtual townhalls preparing for FDA Advisory Committee meetings, BSF remained committed to reducing isolation and building a community where every affected individual and family member feels empowered, understood, and supported.

Community In Action

In 2024, our community of donors, corporate partners, and grassroots fundraisers **powered real progress** for individuals and families affected by Barth syndrome. Your generosity fueled life-saving research, education, and advocacy.

EVENT HIGHLIGHTS



Hockey with a Heart

Raised: $100,000+

The New York Islanders honored individuals with Barth syndrome at their March 23 game. Deacon dropped the ceremonial puck — and became the team's good luck charm in a 6–3 win over the Winnipeg Jets.

Happy Heart Week

Raised: $140,000+

Since its beginnings as a family gathering, the Branagh family's annual event has grown into a **nationwide campaign** — surpassing **$1M raised since inception.**

Athletes in Action

Raised: $13,000+

- **Karina Steigerwald** completed a full 140.6-mile Ironman in under 14 hours.
- **Alex Prizzi** ran 250 miles through Arizona, inspired by his neighbor Wyatt, with supporters donating per mile.

Giving Tuesday 2024

Raised: $106,000+

Peer-to-peer fundraisers shared their stories, reached their networks, and **surpassed our goal** — proving the incredible power of community.

Steven Woodward's Heavenly Birthday

Raised: $9,000+

In honor of what would have been **Steven's 50th birthday**, his loved ones launched a fundraiser for the **31 Fund** — a tribute to his life and legacy.

Steven was the beloved uncle of **Connor, who is affected by Barth syndrome**. The 31 Fund now honors their shared story by supporting **connection, education, and community for Barth families.**

$1.365M IN CONTRIBUTIONS

80+ FUNDRAISERS CREATED BY OUR COMMUNITY ON SOCIAL MEDIA AND PEER-TO-PEER PLATFORMS

SUPPORTING FAMILIES

JULY 29 – AUGUST 3, 2024

Hyatt Regency Coconut Point Resort, Bonita Springs, FL

Coming Together

The 2024 Barth Syndrome International Conference

Reuniting Our Community

The Barth syndrome community gathered for our Biennial International Scientific, Medical, and Family Conference, marking the largest conference in our foundation's history. This landmark event brought together affected individuals, families, researchers, and healthcare providers from across the globe. The conference served as a vital platform for sharing groundbreaking research, fostering collaboration, and strengthening the bonds that unite our worldwide community.

Multiple education tracks:

- Family education and care management
- Research and development
- Continuing medical education (CME)
- On-site research
- Wellness activities

For the first time, we offered continuing medical education credits, reflecting our commitment to advancing healthcare professionals' knowledge of Barth syndrome.

BY THE NUMBERS

94 scientific and medical professionals

38 research posters presented

50 people from 12 families awarded scholarships through newly established travel fund

$207K+ raised for conference

Research and Collaboration

On-site reasearch gave many affected individuals a unique opportunity to advance the scientific understanding of Barth syndrome. Nearly 15% of our global population participated in up to 7 unique IRB-approved on-site research studies. Over 200 research sessions ranging from blood draws to in-depth interviews to longitudinal echocardiogram evaluations were conducted. This collaboration between families and researchers remains the heart of our progress.

SPECIAL EVENTS

Welcome Breakfast

New and returning families connected over breakfast, setting a warm, inclusive tone for the week.

Luminaries Ceremony

A powerful tradition, this candlelit tribute honored everyone ever affected by Barth syndrome, uniting us in remembrance and hope.

Science in a Snapshot

New this conference, eight researchers and clinicians spoke to families in a round-robin style event. Each researcher had 5 minutes to describe their lab's work to a table of families before a bell rung and they moved to the next table of families.

Friday Night Social

"Camp Barth" brought laughter, dancing, games, and connection—an evening to celebrate our community

Conference Finale

Our closing gathering reflected on the week's highlights, leaving attendees inspired and recommitted to the fight against Barth syndrome.

ADVOCACY

Advocating for Our Community

In 2024, the Barth Syndrome Foundation intensified our advocacy efforts to champion the needs of our community, working strategically to influence policy and expand access to treatment options for people living with Barth syndrome.

During Rare Disease Week on Capitol Hill, Barth advocates convened in Washington, DC for meetings with Congressional leaders. We urged the FDA to exercise regulatory flexibility and integrate patient and caregiver perspectives—ensuring fair, thorough reviews of promising therapies for ultra-rare diseases. Regulatory flexibility, authorized by Congress, remains one of the only viable pathways for the approval of new drugs targeting small patient populations, like those affected by Barth syndrome.

We also strengthened alliances with key partners such as the EveryLife Foundation, amplifying our voice in broader health policy discussions. Alongside more than 700 rare disease advocates, our staff and volunteers advocated for Congress's reauthorization of the Rare Pediatric Disease Priority Review Voucher Program—critical to incentivizing drug development for populations with unmet clinical needs.

These coordinated efforts have not only deepened our foundation's relationships with Congressional leadership but have also advanced a unified push to improve access to treatments and streamline regulatory pathways.

BY THE NUMBERS

109
Congressional meetings

16
States represented by advocates

4
BSF trips to Washington, D.C. to advocate in person

Barth Syndrome Awareness Day 2024

April 5, 2024 marked our second annual Barth Syndrome Awareness Day in the US, established through House Resolution 1025. With bipartisan support from 11 congressional representatives led by Rep. Paul Tonko (D-NY-20), this day strengthened our advocacy efforts for the Barth syndrome community.

BSF families and supporters amplified awareness through social media campaigns, personal stories, and profile picture changes. This collective action extended our reach beyond those already familiar with Barth syndrome.

For an ultra-rare condition like Barth syndrome, visibility matters tremendously in our journey toward better outcomes. The success of Barth Syndrome Awareness Day 2024 created nationwide awareness and the need to exercise policies that stand to advance promising therapies into the hands of those who need them.

> *"We're deeply grateful to Rep. Tonko and his congressional colleagues for recognizing the importance of this day. Their support affirms that every individual in our community deserves a chance at treatments, with hope backed by policies and action."*
>
> **EMILY MILLIGAN**
> *Executive Director*
> *Barth Syndrome Foundation*

ADVOCACY

A Historic Victory for Our Community

OUR FDA JOURNEY

On October 10, 2024, the FDA's Cardiovascular and Renal Drugs Advisory Committee (CRDAC) concluded in a 10-6 vote that elamipretide is effective for treating Barth syndrome.

In reviewing the rationales for their votes, committee members underscored the challenges evaluating new therapies in ultra-rare diseases and the importance of regulatory flexibility. Dr. Eric Peterson of University of Texas Southwestern Medical Center "was swayed by the preponderance of the evidence [...] that fell on the side of supporting the drug" attributing his positive vote in large part to "the predominance of responses from the community and from the physicians who are treating these patients". Dr. Gerard Berry of Boston Children's Hospital said, "To deprive somebody of getting the medicine that might help, it's just untenable for me."

The open public hearing was described as "extremely powerful" by Dr. Philip Yeske of the United Mitochondrial Disease Foundation. Annie Kennedy of the EveryLife Foundation wrote the "patient community presentations were a #masterclass in #patientfocuseddrugdevelopment" and highlighted patient experience as the most critical element when considering the totality of the data.

As of December 2024, this therapy remained under FDA review. The Barth Syndrome Foundation was continuing to elevate patient narratives from the open public hearing in pursuit of a positive outcome—one that would mark the first-ever FDA-approved therapy for Barth syndrome.

BY THE NUMBERS

10-6
Advisory Committee vote concluding therapy works

6,000+
people watched online

76
letters submitted to the FDA in support of elamipretide approval ahead of AdComm

ADVOCACY MEANS ACTION

Now more than ever, we must work together to fix the barriers to treatment and research in Barth syndrome. Your gift drives the actions we must take as a community to surmount the challenges we are facing. Every dollar moves us closer. Stand with us—please give today.

Return the enclosed remit envelope or scan the QR code to donate.

STRONGER TOGETHER

Through powerful testimonies, heartfelt letters, and unwavering advocacy, our community has elevated the voices of those affected by ultra-rare diseases and captured the attention of key decision-makers. We have proven that our voices carry weight—and that our resolve is unshakable. We fully recognize the road ahead: ensuring every person with Barth syndrome has access to effective treatments that not only improve quality of life, but also save lives. The Barth Syndrome Foundation remains steadfast in this pursuit and will never, ever give up until progress is achieved. Your continued support—through your time, talent, and treasure—is essential. Together, we are not just raising awareness; we are driving meaningful, lasting change for the Barth community.

RESEARCH

Advancing Research Through Strategic Investment

In 2024, the Barth Syndrome Foundation continued its tradition of catalyzing groundbreaking research through our annual grant program. With generous support from our international affiliates, BSF awarded grants to four exceptional investigators whose work promises to expand our understanding of Barth syndrome and develop potential therapeutic approaches.

Our grant program remains focused on providing seed funding to both established and early-career investigators from across the globe, helping them generate the preliminary data essential for securing follow-on funding from institutions like the National Institutes of Health.

Since 2002, BSF has sponsored over

OVER $7 MILLION IN RESEARCH FUNDING,

which has successfully catalyzed over **$41 million in follow-on funding**—a remarkable 6:1 return on investment.

2024 GRANT RECIPIENTS

Dr. Leonardo Ferreira
Duke University, NC, USA

Dr. Ferreira received a two-year Development Award to evaluate two new drugs that enhance muscle contraction in a mouse model of Barth syndrome. This promising work, conducted in collaboration with SMAB Chair, Dr. Todd Cade, is supported through BSF's Science and Medical Fund.

Dr. Halil Aydin
Formerly University of Colorado, Boulder, CO, now New York University, NY, USA

Dr. Aydin received a one-year Idea Award to investigate how the protein OPA1 might interact with cardiolipin in both control and Barth syndrome conditions, using molecular and structural biology approaches.

Dr. Patrick van der Wel
University of Groningen, The Netherlands

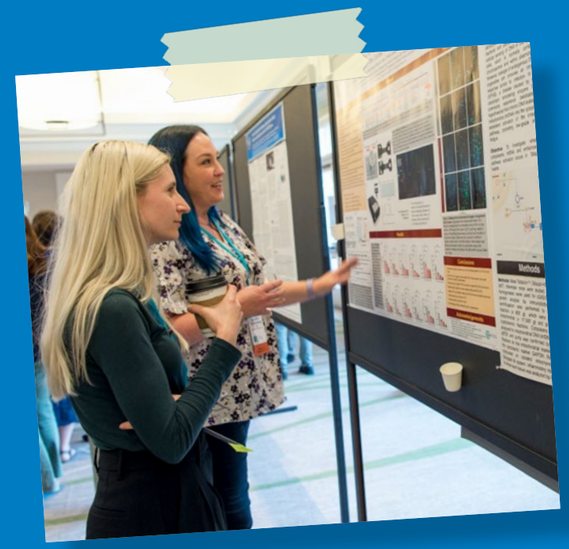
Dr. van der Wel was awarded a 2.5-year Development Award to use structural biology approaches to evaluate inappropriate molecular interactions that occur when TAFAZZIN is mutated and to explore a novel inhibitor of these interactions. This grant was generously supported in part by Association Syndrome de Barth France.

Dr. David Stokes
New York University, NY, USA

Dr. Stokes was granted a two-year Development Award to characterize the human TAFAZZIN protein structure and its interactions with specialized lipids that form membrane structures. This work was generously supported in part by Barth Italia Onlus and Barth Syndrome Foundation of Canada.

Our commitment to advancing Barth syndrome research continues with our annual grant cycle. Each year, we welcome innovative proposals addressing the basic, translational, and clinical research challenges of Barth syndrome, supporting projects ranging from one to three years in duration. By maintaining this consistent investment in scientific discovery, we ensure continual progress toward new treatments and improved quality of life for all affected by Barth syndrome.

For early-career researchers, our partnership with the American Heart Association provides additional funding opportunities through the Predoctoral and Postdoctoral Fellowship program, reinforcing our commitment to nurturing the next generation of Barth syndrome researchers.



RESEARCH

FINDING A CURE

Research & Development Highlights

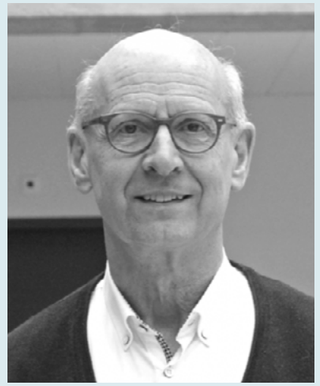
Transformative Progress in Understanding Barth Syndrome

The past year marked significant strides in research and development initiatives, bringing us closer to our mission of finding effective treatments and ultimately a cure for Barth syndrome.

Novel Patient-Tailored Mouse Model of Barth Syndrome

Dr. Simon Conway (Indiana University) and his team have developed a patient-tailored mouse model of Barth syndrome that allows us to understand what roles TAFAZZIN might play in addition to converting monolysocardiolipin (MLCL) to mature cardiolipin. Proteins often perform more than one job in a cell and understanding what the full "job description" of a protein is and how it varies across different organs in the body can be useful for developing targeted therapies or identifying therapies that might be of benefit in a specific organ or particular mutation.

Varner Award Recognizes Long-Time Champion of Barth syndrome Research



Dr. Ronald Wanders

In 2024, BSF's Board of Directors awarded Dr. Ronald Wanders the Varner Pioneer in Science and Medicine Award. The Varner Pioneer in Science and Medicine Award is the most esteemed honor in our foundation, and Dr. Wanders' record of achievement reflects the exceptional quality of research, teaching, and service to the Barth syndrome community. His dedication and commitment to advancing scientific knowledge, serving on BSF's Scientific and Medical Advisory Board, and inspiring the subsequent generation of researchers is truly commendable.

This award is generously supported through the Wilkins family and was established in 2008 in loving memory of Paula and Woody Varner, maternal grandparents to John Wilkins, who embodied persistence, commitment, honor, integrity, and humility. As the recipient of this award, Dr. Wanders joins a distinguished group of individuals who have made remarkable contributions to the central tenets of the Barth Syndrome Foundation's mission to advance treatments, enhancing the quality of life and/or improve the standards of care for those with Barth syndrome.

Chan Zuckerberg Initiative Grant

In a major boost to our research infrastructure, BSF was awarded an $800,000 Rare As One grant from the Chan Zuckerberg Initiative. This five-year funding will accelerate critical research through capacity building by modernizing our patient registry, building out an integrated biobank infrastructure, and ultimately catalyzing novel approaches toward diagnosis, biomarker identification, care management, and treatments. This prestigious grant provides not only financial support, but also access to CZI's vast resource network, facilitating meaningful collaborations that contribute to open science.

Registry Research Reveals New Insights

In collaboration with the Southeast Regional Genetics Network and Emory University, BSF's research team published important findings on the diagnostic odyssey and clinical burden of Barth syndrome. The study revealed that cardiac manifestations lead to faster diagnosis, while also highlighting previously underappreciated gastrointestinal symptoms that could aid in earlier detection and improved clinical management.

Young Investigator Spotlight: Irma Markesina, Iris L. Gonzalez Prize Recipient

PhD student, Irma Markesina, from the University of Rijeka was awarded the Iris L. Gonzalez Prize to analyze data from BSF's Tafazzin Human Variants Database. Her project aims to investigate the molecular consequences of specific Tafazzin mutations by leveraging bioinformatic techniques. She plans to increase the accessibility of the database by integrating it with other widely known databases, making it a richer resource.

Expanding Global Access to Care

There are currently two established centers of expertise/excellence (CoE) with clinical services dedicated exclusively for the care of individuals affected by Barth syndrome: Kennedy Krieger Barth Syndrome Clinic (Baltimore, MD, USA) and the NHS National Barth Syndrome Service (Bristol, UK). Following surveys to the community and a shift in care access outside the US due to geopolitical events, the potential for a CoE in Amsterdam University Medical Center (AMC) was explored. Due diligence was conducted by an external consultant and a business case was established. At the same time, the team at AMC was able to secure two-thirds of the required funding from the Dutch government, which, in combination with funds contributed by BSF allowed the CoE to launch in earnest at the end of 2024. This CoE will offer comprehensive clinical care to the broader EU community of Barth affected individuals and further BSF's mission to ensure access to care for all affected by Barth syndrome.

DONORS

$25,000 & above

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Barth Italia Onlus
Chan Zuckerberg Initiative
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Palmer and Mallory Lummis
Peter and Isabel Malkin
Scott and Laura Malkin
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We thank everyone who has supported Barth Syndrome Foundation at any level!

FINANCIALS

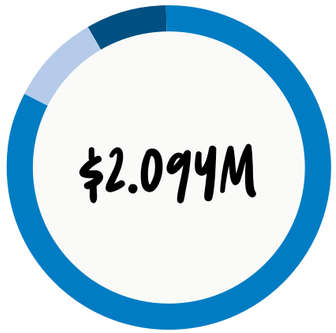
Barth Syndrome Foundation's operations reflect the focus on our mission to save lives through education, advances in treatments and finding a cure for Barth syndrome. In addition, we continue to wisely and strategically invest some of the funds we have collected over time to support therapy development and family services.

We are extremely grateful to our donors for both enabling these important investments and supporting our ongoing operations. BSF remains a financially healthy organization; as of December 31, 2024, the organization has over $5 million in net assets.

2024 Revenue

- **Contributions, Conference, and Grants:** **$1.674M**
- **Net Investment Income** **$257K**
- **Other** **$9K**

2024 Expenses



- **Program Services** **$1.731M**
- **Management & General** **$184K**
- **Fundraising** **$179K**

Figures presented in a manner consistent with BSF's IRS Form 990 and publicly available on our website.

Platinum Transparency 2024
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Raise Your Voice for Those Who Are Rarely Heard

Barth syndrome is ultra rare—and the need for advocacy is urgent. Your support helps us fight for recognition, funding, and a future where every individual with Barth syndrome has access to the care, research, and the community they deserve.

Donate today—see the progress you are making.

Barth Syndrome Foundation®