



## 2022 Giving Tuesday

Giving Tuesday was created in 2012 as a simple idea: a day that encourages people to do good. Since then, it has grown into an annual global movement that inspires hundreds of millions of people to give, collaborate, and celebrate generosity.

For the Barth Syndrome Foundation (BSF), it's a day where our community around the world comes together for 24 hours to raise funds to do important work for our mission. BSF serves a geographically diverse community, making in-person fundraising events impossible for our affected families and friends to participate in and/or attend. That's why Giving Tuesday is so important for BSF. Everyone can participate and every act of generosity, big and small, counts towards building a better world for people with Barth syndrome.

### The Power of Your Donation

- Barth syndrome is an *ultra-rare* genetic disorder. Because of this, your gift is *ultra-important* and directly impacts BSF's ability to serve our medically complex and diverse community.
- BSF is the only global funder uniquely focused on developing treatments for Barth syndrome. Since 2002, BSF has funded \$5.9 million across 120 grants. Reaching our giving goal of \$100,000 this Giving Tuesday will put BSF on track to fund at least 2 new grants in 2023 and to continue research efforts exploring novel approaches to treating this life-threatening disease.
- BSF, in partnership with our 4 global affiliates, provides a lifeline to individuals worldwide by offering 24/7 individualized support to families in medical crisis.
- Funds raised during Giving Tuesday are essential to BSF being able to support a robust research and development portfolio. BSF must raise more than \$1.2 million dollars to advance critical drug development programs in the areas of gene therapy, enzyme replacement therapy, and cardiac care, among others.

## Creating a Giving Tuesday Fundraiser

1. **Click Become a Fundraiser**
  - Join as an individual
2. **Set your fundraising goal.**
  - Increase it if you hit your goal. This will encourage others to give who may not have had a chance yet to contribute. People want to know they are helping you hit a target.
3. **Choose a fundraising end date**
  - Suggested 12/1
4. **Add your headline**
  - Pre-populated with *GIVING more TUESDAYS to people with Barth syndrome*
  - You can change the headline and personalize it with your reason for fundraising for BSF. If so, we suggest a 1-sentence tagline.
5. **Set a short URL:**
  - Ex: [give.classy.org/ \[your name\]](https://give.classy.org/[your name])
    - i. [Give.classy.org/EmilMadalinski](https://give.classy.org/EmilMadalinski)
6. **Upload a profile photo**
  - To compress the photo, you can just open the pic in the viewer, click file-> export. Select jpeg format and adjust the "Quality" slider until the file size is under 2mb

## OUR WORK INCLUDES

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

- Raising awareness among physicians, scientists, and the general public.
- Supporting relevant research through an international grant research program.
- Providing a caring and educational community for affected families; and
- Hosting a unique information resource.

## 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.

## STRATEGIC PLAN

“What can we do at BSF to have a real impact?” This question has been the driver of the strategic plan process for over six months.

The mission and vision remain completely unchanged.

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
- 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.

- \$5.9M USD of research grants have been funded by BSF to date.
- Research tools that can be shared by many, such as the Barth mouse, are key to advancing research, collaboration, and knowledge.
- Natural history studies are extremely important in order to inform clinical trials.
- Specific research focus areas include cardiolipin and mitochondrial physiology, understanding tafazzin mutations and deletions, drug repurposing and disease management.

- Key collaborations that we feel will advance treatments include gene therapy and enzyme replacement therapy.

### ***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.

- BSF intends to continue to leverage technology and innovative approaches to make critical information easily and quickly accessible
- Engage outside experts to help develop important resources, such as GI doctors and cardiologists
- We will be there for our families and affected individuals no matter where you are
- We want to intentionally and explicitly include affected individuals in opportunities to participate and 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.

- Part of our mission is to bring our voice to the table in a way that demonstrates the tremendous unmet needs of our community
- We are exploring an ambassador program – reach out if you are interested
- Barth is a rare disease and is being included in legislative agendas because of BSF
- By sharing our story, we can generate more interest in Barth syndrome, drive future collaborations and find meaningful partners that ultimately will help us drive treatments and therapies. One example of this is funding a health impact study that will show how the burden of disease translates in terms of cost, use of healthcare resources and impact on quality of life.

### ***Never, Ever Give Up!***

No matter the obstacles, we remain committed to our vision and the people we serve. We are #BARTHSTRONG and united.

Hope is not a strategy; we intend to remain accountable and provide updates about BSF's progress every year.