

BSF STRATEGIC PLAN 2021-2023



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!