Together we are making a difference.

Barth Syndrome Foundation

Great science, community, and inspiration

2013 Annual Report

"In this tight funding climate, the Barth Syndrome Foundation has allowed our work, and that of many others, to continue. The Foundation helps to fund, bring together, coordinate, and disseminate research that is truly translational." ~ *Colin Phoon, MPhil, MD, Associate Professor, New York University Medical Center, New York, NY*

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Dear Friends,

We are pleased to report that the Barth Syndrome Foundation (BSF) has had, by all measures, a very good year. We have continued to push forward with our funding of medical research and assistance to families impacted by Barth syndrome while maintaining a strong balance sheet. We are excited about not only the achievements of 2013, but also the foundation laid this year to allow even more substantial progress in the near future.

Your generous support has allowed BSF to explore new frontiers in science and medicine. Our research grants have evolved over the years from simply looking at basic scientific questions to now evaluating potential therapies for the syndrome. The graphic on page 8 of this Report illustrates the momentum and progress we've made, both in terms of the amount of funding that BSF has been able to provide to research as well as the amount of additional research that is now being done without direct funding from the organization. The increased awareness and interest in Barth syndrome research led to a record number of grant applications received by the organization this past year. While much work remains to be done, we believe our strategy of "seeding" research interest in areas implicated by Barth syndrome is paying significant dividends.

Perhaps most exciting about the progress of our research is the identification of a potential drug therapy that we hope (with further confirmation of its potential efficacy) might be ready for clinical evaluation in the next year or so. This potential breakthrough could launch us into an entirely new place offering hope to those affected. Only through the earlier development of the Barth mouse model system, itself a result of funding from the organization, could we be on the brink of this exciting new step toward our ultimate goal of a treatment for Barth syndrome.

With the excitement of having more advanced research into possible therapies for Barth syndrome comes the reality that this research can be very costly. We have thus focused on expanding our awareness and fundraising efforts in many different ways. Our newly-created videos draw the viewer and potential donors in to tell the inspiring story of BSF. In addition, our brand new website now puts important information at your fingertips. With user-friendly navigation, you can easily find important facts and heart-warming stories about this rare disorder. As a result of these tools, the Foundation has seen increased donations, focus, and interest in Barth syndrome.

All of the organizations efforts are made possible by your generosity and support. Your partnership with us has ensured that innovative research gets funded, life-saving information is provided, and loving support is given. With all the important work we were able to accomplish in 2013, we hope and expect that we will have even greater achievements to share with you next year.

We could not do any of this work without … YOU. We thank you for your continued support and hope you enjoy the glimpse into BSF provided by this year's annual report.

With gratitude,

Lindsay B. Groff

Lindsay B. Groff
Executive Director

Marc Sernel

Marc Sernel
Chairman

December 2013: Barth syndrome by the numbers

Known individuals living with Barth syndrome (BTHS)	169 in 21 countries
Increase in number of individuals identified since December 2012	4.3%
Grants funded since BSF was established	78 grant awards totaling $3.0 Million

EDUCATION & SUPPORT

Awareness

Video Win is Worth a Million Words!

We've won "Charities Take Flight!" Pinterest Contest, and if a picture says a thousands words, then a video speaks a million!! Thanks to Parent Advocate Kristi Pena of Mississippi, the Barth Syndrome Foundation won a professionally produced, directed, shot, and edited video to raise awareness. Over twenty charities competed in the Birds Nest Foundation's contest. Submissions took place on Pinterest where entrants pinned photos that best communicated the charity's mission. BSF is proud to be added to their list of clients, and we are pleased to share the videos on our website.

Welcome to the Barth Syndrome Foundation

Our work includes:

New Website Puts Information at Your Fingertips

Thanks to the talented designers at Pixelera and a generous grant from the Max Bell Foundation, the Barth Syndrome Foundation website received a well-deserved makeover. Our revamped website offers users a modern look with intuitive navigation, updated with the latest information about Barth syndrome and our services. We hope that you will enjoy browsing our new site, finding useful information each time, and that it will be yet another tool for strengthening our community. Tell us what you think at bsfinfo@barthsyndrome.org.

www.barthsyndrome.org

Connor Captures Hearts and Spreads Awareness

"If we maintain their health through infancy with supportive heart care, their prognosis is good," says pediatric cardiologist Reid Thompson. "The riskiest times are during the first year of life and in puberty, when these patients require more protein and their heart and other muscles demand more energy to function properly." ~ *Reid Thompson, Pediatric Cardiologist, Johns Hopkins*

The winter edition of the Johns Hopkins Medicine Pediatric Heart News featured sweet, little Connor. Connor's parents take full advantage of the Barth Syndrome Clinic at the Kennedy Krieger Institute.

Family Services

> **"Because of BSF, through the website, the conference, alerting us to the specialists at KKI, and the listserv, we have become empowered. We are able to be sure that Jack receives the care and treatment he so deserves. I know that we are Jack's best advocates. We are the best because of the knowledge we have received from BSF."** ~ *Rachel, Mom*

Jack, age 3, and his sister, Elise

JACK

Our life was a mess. Brian and I, two responsible, organized, young professionals couldn't believe what was happening. Brian's mom was at home in stage 4 lung cancer, and we were in the CICU at Children's Hospital in Pittsburgh watching residents and attending doctors swarm around our son discussing diagnosis possibilities. One resident mentioned Barth syndrome, and that caught Brian's ear. Brian visited Barth Syndrome Foundation's (BSF) website and contacted BSF from the hospital. He spoke with Shelley who gave information as well as much-needed support.

At age 6 months, our precious Jack was diagnosed with Barth syndrome.

BSF has given us a special gift. BSF has empowered us with knowledge. Through BSF's website, we have access to factual information to provide to Jack's doctors and caregivers to enable them to provide quality care to Jack. It is so easy to print out a fact sheet and hand it over, rather than try to find the words to explain.

While attending the 2012 conference, we were able to talk with specialists whom we would otherwise never have met. This was the first time we were able to connect with other families and to see, in person, that Jack was not the only person on Earth with Barth syndrome. Everyone had a smile, some even a hug, and we never felt like strangers.

We learned about the Kennedy Krieger Institute (KKI) through BSF shortly after Jack was diagnosed, and Jack was able to receive care from the specialists there. Jack now annually attends their Barth Syndrome Clinic. It is refreshing to speak with specialists who are knowledgeable about Barth syndrome. I leave KKI with new information each time we visit.

I joined BSF's listserv, which is like being at an online version of a family session at the conference. I post a question, and I am sure to receive a response with an avenue to explore.

Because of BSF, through the website, alerting us to the specialists at KKI, and the listserv, we have become empowered. We are able to be sure that Jack receives the care and treatment he so deserves. I know that we are Jack's best advocates. We are the best because of the knowledge we have received from BSF.

Jack and Connor look to the future!

(L-R) Jack, and his "Barth buddy", Connor, both age 3, look to the future while their families attended the Labtrobe, PA Family Outreach in June of 2013.

Family Support

> **"Suddenly we had a vast set of educational resources on all things Barth syndrome to lean on for a more targeted treatment. Best of all, we gained a network of affected families whose experience, strength, and hope would help shape Greyson's journey."** ~ *Eric, Dad*

Greyson, age 6

Greyson proudly wears the 2013 Ironman Finisher's Medal given to him by Ghent Lummis, a member of Team Will.

GREYSON

We first heard of Barth syndrome a few weeks after Greyson's troubles began in earnest. At two months, a cardiothoracic surgeon told us that he might go to kindergarten with his heart but that he wouldn't graduate high school with it. Specialists, doctors, and intensivists immediately descended on treatments, testing, and medications with the hope of finding the diagnosis of Greyson's baseball-sized heart. Early results showed a small constellation of issues; however, the first genetic tests for Barth syndrome were reported as negative. A second test was done while being on the list for a new heart, and this one came back as inconclusive. Without diagnosis, we could only hope that his heart would stabilize during these early months of life.

Initial treatment did allow Greyson's heart to steady at a stronger rate, but it was still a "weak pumper". Fourteen months went by with us doing a new shuffle of doctor visits, medications, and research. We even saw an episode of 'Mystery Diagnosis' featuring Shelley Bowen's family. Then our foretold day came, and we knew it was his heart going into failure. Our local children's hospital life-flighted our boy to a larger pediatric facility with more specialized training. Greyson was back on the waiting list for an organ donor. Only days later, he went into a full cardiac failure. In an emergency procedure, an incredible piece of equipment called the Berlin Heart was implanted to his heart, elevating him to the top of list. A third test for Barth syndrome was sent out for study. Now all we could do was watch and wait while the cardiac intensive care staff took care of our baby.

Greyson only had four days to wait for his angel heart. His recovery was not without complications, but he was proving to be a resilient little fighter that adapted to every challenge. We were going to get to bring the boy home. That is all that mattered. But still we would have to wait for a diagnosis, if there even was one.

The doctors called just weeks later to tell us that without a doubt this time there was an answer: Barth syndrome.

Family and friends both emailed and called the Barth Syndrome Foundation on our behalf. Just three days later, the Wilkins family visited our home, and we instantly knew we were not alone anymore. Shelley Bowen then gave us a courtesy call that lasted a couple of hours. Suddenly we had a vast set of educational resources on all things Barth syndrome to lean on for a more targeted treatment. Best of all, we gained a network of affected families whose experience, strength, and hope would help shape Greyson's journey.

2013 Family Services Spotlight

- Provided education and support for 169 affected individuals and their families throughout 2013
- Increased the number of affected individuals and families who BSF and/or BSF affiliates serve by 4.3%
- Monitored the family listserv with a total of 3,109 posts

SCIENCE & MEDICINE

Barth Syndrome Researcher Wins Prestigious E. Mead Johnson Award for Outstanding Pediatric Research

BSF congratulates Dr. William Pu, Associate Professor, Harvard Medical School, Department of Cardiology, Boston Children's Hospital, Boston, MA, on receipt of the E. Mead Johnson Award for Research in Pediatrics at the 2013 annual meeting of the Pediatric Academic Societies. This prestigious award honors outstanding clinical and laboratory research achievements in pediatrics. Dr. Pu presented a talk at the meeting titled "Modeling cardiomyopathy using human induced pluripotent stem cells".

Dr. Pu has advanced the understanding of mechanisms that regulate heart development and adult heart function. His work has revealed transcription factors and transcriptional regulatory mechanisms that control heart morphogenesis and the stress response of the post-natal heart. Dr. Pu's research has also highlighted the contribution of distinct cell types to formation, vascularization, and injury responses of the heart. Most recently, Dr. Pu's research has used insights from heart development to uncover new potential approaches to improve heart repair and regeneration.

Exciting Changes to BSF Research Grant Program

Starting in 2013, the BSF Research Grant program was modified to include two types of grant awards: **IDEA** grants for 1-2 years and **DEVELOPMENT** grants for 2-3 years with budgetary maximums of $50,000 or $100,000, respectively, over the full period. BSF's Research Grant Program allows young, non-tenured investigators to include in their submitted budget up to 75% of the direct costs amount as Principal Investigator salary. In addition, for those clinical applications where volunteers must travel to a clinical research site, these travel expenses will be handled separately and will not be included in the application budget limitation. We encourage all investigators at every professional level to submit their best ideas for advancing the state of knowledge about Barth syndrome so that progress can be made in finding a specific treatment or a cure for this unusual mitochondrial disease. There are no geographical limitations to this funding.

BSF Receives Orphan-Drug Status for Bezafibrate

On July 24, 2013 the Barth Syndrome Foundation (BSF) received Orphan-Drug Designation for bezafibrate for the "treatment of Barth syndrome." This achievement allows BSF and researchers to focus on studying this drug to determine if it is safe and effective for Barth syndrome individuals. The next step in this process is to file an Investigational New Drug application with the Food and Drug Administration (FDA) which explains in full detail how we are going to test this drug. This lengthy and ongoing process has only been possible through the outstanding help of: the SMARTT group at the National Heart, Lung, and Blood Institute; the license holder of bezafibrate (Tribute Pharmaceuticals); and the healthcare professionals who are planning and will perform the clinical study (Drs. Todd Cade and Dominic Reeds). Like the movie The Perfect Storm (but in a good way), these three independent groups have come together with BSF to test the first drug specifically identified for treating Barth syndrome individuals. This paragraph is just a small update to the "story to be continued." As we go forward, the BSF community will have its crucial part to play. In the meantime, a study on bezafibrate and resveratrol is being developed in the UK.

Co-Sponsored Cardiolipin Mini-Meeting in Bari, Italy

"The idea of a Cardiolipin workshop in Italy came to the meeting organizers in June 2011, during the mini-sabbatical of Angela Corcelli in New York City in the Laboratory of Michael Schlame. They thought to take advantage of the presence of the 54th International Conference on the Bioscience of Lipids (ICBL) at Bari in 2013 to organize the Cardiolipin workshop as a satellite event. The web page of the Cardiolipin Meeting was kindly supported by the Euro Fed Lipid organization. On September 17, 2013, about 60 scientists attended the meeting focused on the multiple roles of cardiolipin in mitochondria in physiological and pathological states in various organisms as well as in bacterial membranes. In addition to ICBL participants, many students and colleagues of the Universities of Bari and Lecce attended the meeting, increasing the number of total participants to about 100. As defects in cardiolipin metabolism may cause Barth syndrome, the meeting also presented an occasion to establish contacts between the nascent Italian Barth Syndrome Foundation and scientists actively involved in cardiolipin research." [Corcelli A, Schlame M. **Cardiolipin as key lipid of mitochondria in health and disease.** Meeting Report – September 17, 2013, Bari, Italy. Eur. J. Lipid Sci. Technol. 2013, 115, 0000–0000.* *(Abstract)*]

Research Grant Program

With the completion of the 2013 Barth Syndrome Foundation (BSF) Research Grant Cycle, 12 annual award cycles have committed a total of $3.0 million to this important effort through 78 research grants to 46 principal investigators around the world. As with all BSF grant cycles, the projects from the 2013 cycle that were accepted by BSF actually were awarded the following year, thus being included in 2014 fiscal year expenses. BSF, with the advice of its international Scientific Medical & Advisory Board, and with support from international affiliates, awarded six research projects. Starting in 2013, BSF awarded two types of grant awards: IDEA grants for 1-2 years and DEVELOPMENT grants for 2-3 years with budgetary maximums of US $50,000 or $100,000, respectively, over the full period.

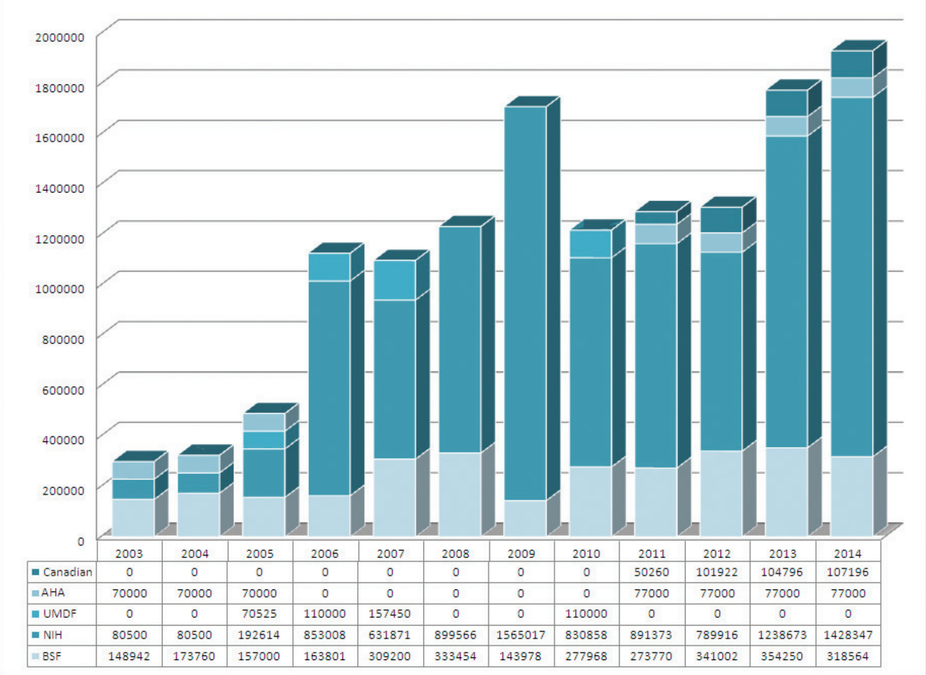
This competitive grant program has resulted in many publications which further describe scientific and medical components of this multi-faceted disease and are leading towards new ideas for treatment. A complete list of all grant awardees can be found on BSF's website at **www.barthsyndrome.org**, and those receiving awards in the 2013 cycle are:

	William T. Pu, MD, Associate Professor, Boston Children's Hospital; Boston, MA **Reactive oxygen species and mitochondrial dynamics in the pathogenesis of Barth syndrome** Award—US $100,000 over 2-year period		Stacey Reynolds, PhD, OTR/L, Associate Professor, Virginia Commonwealth University; Richmond, VA **A systematic investigation into sensory and motor based feeding issues in boys with Barth syndrome** Award—US $18,732 over 1-year period *Funds provided by Association Barth France*
	Miriam Greenberg, PhD, Professor and Associate Dean, Wayne State University; Detroit, MI **Identification of human cardiolipin phospholipases that are deleterious to *tafazzin*-deficient cells** Award—US $50,000 over 1-year period		Grant Hatch, PhD, Professor, University of Manitoba; Winnipeg, Manitoba, Canada ***Tafazzin* knockdown alters hepatic lipid metabolism** Award—US $49,995 over 1-year period *Partial funding provided by BSF of Canada*
	Douglas Strathdee, PhD, Head of Transgenic Technology, Beatson Institute for Cancer Research; Glasgow, Scotland **Characterization of a conditional knockout of *tafazzin* in the mouse** Award—US $49,837 over 2-year period *Funds provided by Barth Syndrome Trust, UK*		Nathan N. Alder, PhD, Assistant Professor, University of Connecticut; Storrs, CT **Investigation of cardiolipin-dependent respiratory complex activity and development of small molecule lipid analogs** Award—US $50,000 over 1-year period

BSF Research Funding Sources

(by fiscal year)

BSF's smaller research grants are meant to attract talented researchers whose initial work then successfully receives greater funding from larger institutions. Our strategy continues to produce great results!



	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Canadian	0	0	0	0	0	0	0	0	50260	101922	104796	107196
AHA	70000	70000	70000	0	0	0	0	0	77000	77000	77000	77000
UMDF	0	0	70525	110000	157450	0	0	110000	0	0	0	0
NIH	80500	80500	192614	853008	631871	899566	1565017	830858	891373	789916	1238673	1428347
BSF	148942	173760	157000	163801	309200	333454	143978	277968	273770	341002	354250	318564

FINANCES

With continuing diligence, the BSF team makes every dollar you donate work as hard as possible. Together, the staff and Board ensure that the endorsement of the Better Business Bureau Wise Giving Alliance and the National Health Council continues to be earned, and that their 20 Standards of Accountability and 43 Standards of Excellence, respectively, are applied to all we do. Your dollars are what fuel the increasingly positive impact we are making on Barth syndrome, and your continued support ensures that this progress will be maintained. We understand that it's your faith in us which ensures that support.

Your donations matter. Every single dollar helps, and all ideas are welcome. From bowling tournaments to community-wide walks, we will provide the information you need to host a fundraiser, so please don't hesitate to contact us with ideas. You are making a difference in the lives of those affected by Barth syndrome!

Blades for Barth 2013

Statement of Financial Position

December 31, 2013 (with comparative totals for year ended December 31, 2012)

Assets

	12/31/2013	12/31/2012
Assets:		
Cash & cash equivalents	$ 723,721	$ 565,387
Investments	1,150,883	1,303,620
Accounts receivable	21,828	37,186
Prepaid expenses	12,118	3,592
Total assets	**$ 1,908,550**	**$ 1,909,785**

Liabilities and Net Assets

	12/31/2013	12/31/2012
Liabilities:		
Accounts payable & accrued expenses	$ 23,478	$ 29,938
Grants payable	38,815	60,500
Total liabilities	**62,293**	**90,438**
NET ASSETS:		
Unrestricted	911,867	849,083
Temporarily restricted	934,390	970,264
Total net assets	**1,846,257**	**1,819,347**
Total liabilities & net assets	**$ 1,908,550**	**$ 1,909,785**

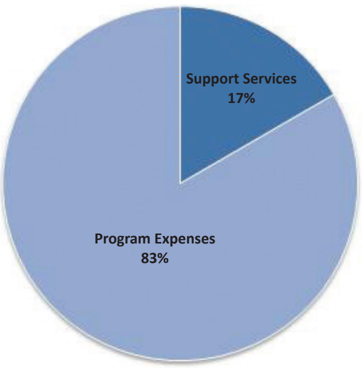
*See annual audit for notes and additional information

Statement of Activities

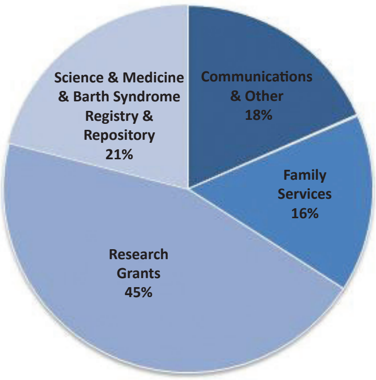
For the Year Ended December 31, 2013 (with comparative totals for the year ended December 31, 2012)

	Year Ended 12/31/13	Year Ended 12/31/12
PUBLIC SUPPORT AND OTHER REVENUES:		
Public Support:		
Contributions	$ 824,480	$ 871,480
	824,480	871,480
Investment Income	5,481	7,975
Unrealized Gain (Loss) on Investments	(6,099)	990
Total Public Support & Other Revenues	**823,862**	**880,445**
EXPENSES AND LOSSES:		
Program Services:		
Communications & Other	122,097	100,710
BSF Conference	839	123,515
Family Services	103,484	78,148
Barth Syndrome Registry & Repository	(46,845)	4,800
Research Grants	344,226	340,823
Research Grants Funded Directly by BSF of CA	(45,948)	(40,000)
Science & Medicine	186,369	171,408
	664,222	**779,404**
Supporting Services:		
Management & General	82,489	137,384
Development & Fundraising	50,241	39,521
	132,730	176,905
Total Expense & Losses	**796,952**	**956,309**
CHANGE IN NET ASSETS	26,910	(75,864)
NET ASSETS, beginning of year	1,819,347	1,895,211
NET ASSETS, end of year	**$1,846,257**	**$ 1,819,347**

All Expenses



Breakdown of Program Expenses



Note: BSF's full 2013 audited financials are available on our website at **www.barthsyndrome.org**.

LEADING THE WAY

The Barth Syndrome Foundation's (BSF) Board of Directors provides oversight of governance, fundraising efforts, and the overall guidance of BSF, while BSF's International Scientific & Medical Advisory Board offers expertise that is invaluable to the mission and future of our organization. Finally, BSF is privileged indeed to have the support of key partners from the public and private communities that provide the bulk of the funding for our programs. BSF wishes to thank and recognize all of the individuals for their hard work and dedication.

Barth Syndrome Foundation
PO Box 618
Larchmont, NY 10538

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2013 DONORS

PAULA & WOODY VARNER FUND

Stars ($5,000+)

Wilkins, Muriel

Angels ($1,000 - $4,999)

Sonderegger, Ted & Mary Ann
Wilkins, Sue & Dr. Mike

General Contributions ($50 - $999)

Acklie Charitable Foundation
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Wilkins, Dr. Lee & Kristy
Wilkins, Joanne
Wilkins, John
Zeitner, Eric & Katrina

SCIENCE & MEDICINE FUND

Stars ($5,000+)

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Sernel, Marc & Tracy

Angels ($1,000 - $4,999)

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Forsyth, John & Linnet
Geary, Ann
Haines, Dr. Tom
Kirkland and Ellis Foundation
Kugelmann, Peter & Karen

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Nurkowski, John
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Robinson, Joe & Connie Sue
Sampson, Dr. Hugh & Anne
Schwendener, Paul & Barbara
Stahly, Craig
Steer - In
Theraplay, P.L.L.C.
Tulchin, David & Nora
Watson, Theda

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Stars ($5,000+)

American Express Gift Matching
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Buly, Dr. Robert & Lynne
Clapp, Eugene
Frill Foundation
Good Harbor Financial LLC
Lummis, William & Dossy
Malkin, Scott & Laura
McCurdy, Steve & Kate
Christopher McKown Charitable Gift Fund
Miller, Kirt & Martha
Newmark & Company Real Estate Inc.
Pierson, Dr. Richard & Allene
Robinson, Frank & Sharon
Russell, Dr. Paul
Sernel, Gordon & Sharon
Earl and Brenda Shapiro Foundation
The Lebensfeld Foundation
The Malkin Fund
Tortimaki Foundation

Angels ($1,000 - $4,999)

American Express PAC Match
Anonymous
Bailey, Clarke & Trish
Barad, Seth & Amy
Dillon Foundation
Eleanor Minor Trust
Epstein, Paul & Leah
Evoy, Larry & Sally
Flatt, Andrea
Susan & David Fowler Charitable Gift Foundation
Glenn, William
Grubb & Ellis
Hales, Bryan
Hart, Dana
Hechinger Family Charitable Gift Fund
Heine, Timothy
Holly, Greg & Keli
Ingersoll, Ann
Isaac, Paul & Karen
Johnson, Malcolm & Deloris
Kuhl, Phillips & Karen
Lummis, Ghent
Emily Mason Malkin Fund
Louisa Rice Malkin Fund
Rebecca Swift Malkin Fund
Mann, Allen & Rosa
Masterson, Moira
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> **"I have been involved in a number of volunteer organizations and have to say the BSF group is quite outstanding. Started from a small set of dedicated volunteers, this group went from being concerned parents to a highly professional organization that is driving research and results for the affected population around the world. Everyone involved cares deeply about the families and the affected boys and men, and it shows in everything they do."** ~ *Lynn, Volunteer and Mother of son with Barth syndrome*

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"Life before BSF can be characterized by one word, isolation. Isolation from informed doctors and researchers, from necessary services, from other affected boys and families, and from support of any nature. Life since BSF can be characterized by one word, teamwork." ~ *Rosemary, Mother of son with Barth syndrome*

"Our son is affected by this disease and when he was diagnosed over 10 years ago, the Barth Syndrome Foundation dramatically changed his path of treatment and has been a life line for us. The medical advisory staff are incredible! The people involved and the families affected are extraordinary!" ~ *Julie, Mother of son with Barth syndrome*

"BSF has made such a huge difference in our life when our grandson was diagnosed with Barth syndrome when he was 3 months old. We were overwhelmed with questions nobody could answer and we found in BSF a wonderful community of parents and experts offering knowledge, advice and support." ~ *Madeleine, Grandparent of individual with Barth syndrome*

Our Mission

Today, Barth syndrome is a rarely understood, frequently fatal, genetic disorder primarily affecting males. The Barth Syndrome Foundation is an engaged, global community whose mission is...

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

Thank you for your generous gifts that made all of this possible. We hope you will continue to support us so that we may continue to offer these vital programs to Jack, Greyson, and all the boys and young men affected by Barth syndrome.

"Initially I got involved with this cause and the Ironman itself because I knew a boy who had Barth syndrome. Now, I remain committed to this cause because of all those who have Barth syndrome." ~ *Ghent Lummis, Member of Team Will*

With your help, we are moving forward together!

Thank you for making a difference in the lives of those affected by Barth syndrome.

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