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

Ty (age 1)

Barth Syndrome Foundation Annual Report 2014

Dear Friends,

Recently, I received a donation in the mail from a long-time supporter of BSF. She told me this, "I've been giving to the Foundation since the beginning. Back then, there seemed to be very little hope. But, after reading your letters and updates, I can see now that there really is hope! I'm so happy I can support your work. These boys and young men need hope."

I was overcome by emotion from her words because she is right…now there really is hope. And it's thanks to her support and **YOURS**!

2014 was bursting at the seams with hope. Thanks to you, we raised over a million dollars in donations. And, we put that money to good use to help our boys and young men suffering from Barth syndrome.

As you'll see in this report, we funded some truly promising research. We've arrived at this new frontier in science and medicine where we are actually getting close to therapies for Barth syndrome. There is currently no specific treatment for Barth syndrome. Right now, we only treat the symptoms, and that's where the work of the Foundation comes in. No other organization is dedicated to finding treatments for Barth syndrome.

Thanks to you, we can keep fighting for answers. We give hope to new moms like Elissa whose story you'll read in this report. Thanks to you, we continue to raise awareness and educate families and clinicians. Thank you for giving us hope!

As we move into 2015, let's keep the hope alive. With your help, we can continue this good work. We will push for treatments. We will provide loving support to our families, and we will do all of this, thanks to **YOUR** generosity.

With gratitude,

Lindsay B. Groff

Lindsay B. Groff
Executive Director

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Letter from the Chairman

"It was the best of times, it was the worst of times." That is how I feel about the year our Barth Syndrome Foundation family had in 2014.

The good news is that the Barth Syndrome Foundation is as healthy as ever. We continue to expand the reach of the organization while keeping the balance sheet strong. Thanks to the generosity of our donors we set new records in fundraising with over $1 million in donations received. We hosted another wonderfully successful biennial conference in Florida last June with record attendance and high marks from scientists and families alike. Progress of our scientific and medical research continues to accelerate, with different therapeutic possibilities now closer to reality than ever before. We have built on the progress of the past and have put the organization in position for even greater breakthroughs in the near future.

Will
1/23/86—10/25/2014

However, 2014 was also the worst of times, with painful reminders of the gravity of the syndrome that this organization is tasked with eradicating. Dear members of our organization lost their struggle with Barth syndrome last year, and many others continue to suffer through heart transplants and other serious health challenges. Barth syndrome continues to be a fatal disorder, and all of the hard work and great progress we've made since the founding of the organization 15 years ago, unfortunately, has not changed that harsh reality. We are in a race against time to find a treatment or cure for this deadly disorder for those affected and those who will be affected in the future. And 2014 reminded us that the stakes could not be higher.

While we did grieve for those lost in 2014, we have done our best to channel our emotions in a positive direction, re-doubling our efforts to achieve our ultimate goal of finding a treatment or cure for Barth syndrome. The establishment of the Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome is a testament to Will's positive spirit and "will" to never give up. We will never give up pursuit of this organization's goals, and with your help we look forward to the day when suffering from Barth syndrome is a thing of the past. Thank you for your continued support.

Marc Sernel

Marc Sernel
Chairman

December 2014: Barth syndrome by the numbers

Known individuals living with Barth syndrome	**185** in **26** countries
Increase in number of individuals identified since December 2013	**9.4%**
Number of individuals enrolled in Barth Syndrome Registry 2.0	**46**
Research grant awards funded since BSF was established	**87** totaling **$3.5 Million**
Percentage of BSF Staff and Board members who donated in 2014	**100%**

AWARENESS

"I was deeply affected by a Barth syndrome patient, and others with poorly characterized genetic disorders. I wanted to figure out what was happening inside their bodies, to help them lead normal lives." ~ *William T. Pu, MD, Associate Professor of Pediatrics, Harvard Medical School; Department of Cardiology, Boston Children's Hospital, Boston, MA*

William T. Pu, MD

BSF Seed Funding Helps Create Medical Research Breakthrough

"Heart on a Chip" Recognized for Innovation

With seed funding from the Barth Syndrome Foundation (BSF), Dr. Pu created a medical research breakthrough, "Heart on a Chip". Although more testing is needed, this innovation could help unlock answers about Barth syndrome. It could also lead to discoveries in other diseases. Through collaboration across multiple fields of biology and engineering, this work elevates organ-on-a-chip technology to a new level and sets a powerful precedent in medical research. This is at the forefront of personalized medicine, which is creating such a buzz these days.

BSF isn't the only organization excited about this development. The American Heart Association recognized "Heart on a Chip" as one of the top ten cardiovascular disease research advances of 2014. Quite an honor! [Wang et al. **Modeling the mitochondrial cardiomyopathy of Barth syndrome with induced pluripotent stem cell and heart-on-chip technologies.** Nat Med. 2014 Jun;20(6):616-23. doi:10.1038/nm.3545 Epub. 2014 May 11.]

Dr. Pu first met children with Barth syndrome during his training about twenty years ago. "I was deeply affected by a Barth syndrome patient, and others with poorly characterized genetic disorders," recalls Dr. Pu. "I wanted to figure out what was happening inside their bodies, to help them lead normal lives." He still sees patients, but Dr. Pu now spends most of his time in the lab. He presented his findings at the 2014 BSF Conference in Clearwater, Florida. He is a multiple awardee of the BSF Research Grant Program and a member of BSF'S international Scientific and Medical Advisory Board.

The Foundation provided seed funding for Dr. Pu's research and also helped him obtain key skin samples from two Barth syndrome patients that he needed to do his work. "Several important lessons, beyond those that are obvious, can be learned from Dr. Pu's wonderful project," said Kate McCurdy, a BSF founding Board member. "First, it demonstrates that donating precious biological specimens is one way in which laymen make critically important contributions to scientific advancement. It also offers a perfect example of how work that is first done in a rare disease setting can end up having much broader scientific and medical applicability and impact."

Many of the clinicians and scientists at BSF's 2014 Conference.

Many of the boys and young men at BSF's 2014 Conference.

FAMILY SERVICES

"The BSF community were always there to offer parent-to-parent advice, reassurance, and hope. They have given me so much strength. Although some things were terrifying to learn, I know my son's life depends on me. I understand the importance of my role as Eli's mother and number one advocate." ~ *Elissa , Mother of Eli, Australia*

(Photo courtesy of Rhona Pinasco Photography)

Meet Eli

Our first child, Eli, was born on Valentine's Day last year, by far the happiest day of our lives! We were living in a big bubble of love. Life was perfect.

Two weeks in, our bubble burst. Our happy little world became a dark, uncertain place. On Eli's 17th day, things just didn't seem right. He wasn't feeding; he was lethargic and cold. We rushed him to emergency. Within minutes, he was in a critical condition in intensive care, being resuscitated by swarms of doctors and nurses. We stood there shell-shocked and helpless, as we watched them work on our tiny, fragile son for hours. It felt like a lifetime. We prayed so hard for our son. We fell overwhelmingly in love with this little man; I couldn't bear to think of life without him.

Our prayers were answered that night, as Eli lived to fight another day. Little did we know that was just the beginning of our adventure. We spent the next two months in intensive care. Family and friends came to meet Eli for the first time as he lay in a hospital bed, intubated with tubes and lines everywhere nothing like we'd imagined.

When Eli was 7 months old, we received a call late one evening from our cardiologist.....a phone call, from a doctor, late in the evening? Alarm bells were ringing! He informed us that a diagnosis for Eli had been found—Barth syndrome. Instantly, I had loads of questions. What is Barth syndrome? How did he get it? What are the symptoms? How do you spell it? And most importantly....how do we fix it?

When I put the phone down, I didn't know how to feel. Happy? We have a diagnosis. Worried? Now there are more known elements to his illness. Terrified? What exactly does this mean for our precious little man?

Instantly, I was Googling "Barth syndrome". I needed to know more. I came across the Barth Syndrome Foundation (BSF) website and emailed one of the founders, Shelley Bowen. I read some of the information and then sat and processed it. Tears started to flow. Tears for the lost glimmer of hope I had that Eli would get better and for the "label" he now gained.

Before I knew it, I was Skyping with Shelley from the other side of the world. Shelley was a complete stranger, yet I openly shed my tears and fears with her. She answered all of my questions and told me everything I needed to know. I was so grateful to speak with someone knowledgeable, yet personable.

I gained the knowledge needed to feel more at ease. I was then ready to share our news with family and friends. They all seemed happy when I told them a diagnosis had been found, but I still wasn't sure how I felt about it. Then the emails and Facebook friend requests came flooding in. I learned about this wonderfully supportive community, and before my eyes, we were welcomed by a truly amazing group of people. This sense of belonging helped me to overcome my fears, accept our fate, and move forward for the sake of Eli.

Over the coming months, many of our questions were answered. The BSF community were always there to offer parent-to-parent advice, reassurance, and hope. They have given me so much strength. Although some things were terrifying to learn, I know my son's life depends on me. I understand the importance of my role as Eli's mother and number one advocate.

2014 Family Services Spotlight

# of appointments kept for research studies & consultations at conference	**297** out of **307**
2014 conference video views on BSF YouTube page	**1,902**
Community interactions via listserv posts	**2,735**
"Likes" on BSF Facebook page	**1,023**

Conference

"As a physician-scientist working in the field, I cannot say enough good things about the Barth Syndrome Foundation. Like many worthy non-profit organizations, they focus on a rare but devastating disease. Like many non-profits, they raise money for research and heighten awareness. Like many other non-profits, they are a tight-knit community. What I think sets the BSF apart is the biennial International Scientific, Medical, and Family Conference, which brings together not only scientists, doctors, and other healthcare professionals, but families and patients too. The conference then takes on a personal quality. The science and medicine of the disease we're discussing are intertwined with the personal side, at this truly inspiring conference." *~ Colin G. Steward, PhD, FRCP, FRCPCH; Bristol Royal Hospital for Children, Bristol, England*

7th International Scientific, Medical & Family Conference

Conference attendees form in the shape of BSF's logo on the beach.

Over 330 people attended the Barth Syndrome Foundation (BSF) 7th International Scientific, Medical & Family Conference, held in Clearwater, Florida in June 2014. Seventy five of these attendees were researchers, physicians, and healthcare professionals, making it the largest scientific gathering dedicated to discussing Barth syndrome ever convened.

The Scientific and Medical (SciMed) sessions were held over two days, covering topics such as: Mitochondrial Lipids, Clinical Studies on Barth Syndrome, Mitochondrial Physiology, and Animal Models. A Poster Session took place and four poster authors were selected to speak about their work.

The 2014 Conference was hailed as an outstanding success by Barth syndrome family members, clinicians, and researchers. More than half of the SciMed attendees indicated this was their first BSF Conference, and more than 95% stated they would attend a future conference. This demonstrates that interest in Barth syndrome has expanded for researchers and clinicians which, in turn, will lead to even more progress in combatting this disease. (2014 Conference presentations can be found on BSF's website.)

Varner Award for Pioneers in Science and Medicine

John Wilkins presented the Varner Award to Dr. Iris Gonzalez.

Iris L. Gonzalez, PhD (Research Scientist, Molecular Diagnostics Lab, A. I. duPont Hospital for Children; Wilmington, DE) knows more about the details of the *TAZ* gene than anyone else in the world. She was presented with the Varner Award for Pioneers in Science and Medicine at BSF's 2014 Conference. This award is given to a scientist or physician whose dedication to work has made a positive and lasting impact on Barth syndrome.

Dr. Gonzalez became involved with BSF in 2000 when she was invited by Dr. Richard Kelley to attend BSF's first-ever family gathering. Over the years, Dr. Gonzalez has made a number of important scientific contributions to BSF. These include (1) serving as member of BSF's Scientific & Medical Advisory Board since its inception; (2) conducting research funded by BSF; (3) creating and maintaining the most comprehensive database of huamn *TAZ* gene variants; (4) playing a vital role in keeping communications open between molecular geneticists at diagnostic laboratories; and (5) producing a layman's guide to genetics that has been extremely valuable to our Barth families.

Dr. Gonzalez's 2002 grant award ("A Study of *TAZ* mRNAs in Barth Syndrome Individuals") resulted in a published article in the American Journal of Medical Genetics entitled, "Barth syndrome: *TAZ* gene mutations, mRNAs, and evolution".

Dr. Gonzalez is the epitome of a pioneer in science for Barth syndrome. BSF is grateful for her many contributions, continued expertise, interest, and support. When the award was presented to her she said, "I want to thank my Barth family once again. This is my Nobel Prize!" (2014 Varner Award Presentation can be found on BSF's website.)

"Iris is a first-rate scientist with a very human perspective. She operates in the realm of cutting-edge science but never forgets that the samples she deals with and the mutations she analyzes come from boys and young men who are real people who are sons, brothers, nephews, grandsons, husbands and yes, even fathers." *~ Family Member, BSF Community*

"Iris has freely donated hundreds, if not thousands of hours of her expertise to Barth syndrome and has done more for understanding the genetics of Barth syndrome and *TAZ* function than anyone else by at least an order of magnitude. A remarkable scholar indeed." *~ Richard I. Kelley, MD, PhD, Kennedy Krieger Institute, Johns Hopkins University, Baltimore, MD*

SCIENCE & MEDICINE

Exciting Changes to BSF Research Grant Program

Starting in 2014, the Barth Syndrome Foundation (BSF) Research Grant program was modified to include two Request for Applications (RFAs) for work in clinical areas that have been under-explored to date. These RFAs are in addition to the usual, broad appeal for research grant applications on Barth syndrome. The goals of BSF´s Research Grant Program are to advance scientific knowledge of the basic mechanism of the disease and to develop improved medical therapies for children and adults affected by Barth syndrome. *(See page 8 for 2014 grant awardees.)*

BSF Seed Funding Leads to National Institutes of Health (NIH) Grants

Dr. Greenberg

Support from BSF has enabled Miriam Greenberg, PhD (Professor, Biological Sciences, Wayne State University, Detroit, MI) to carry out Barth syndrome-focused research that has led to subsequent NIH funding. Dr. Greenberg's first BSF grant from the 2002 grant cycle ("*TAZ1* Gene Function in Yeast: A Molecular Model for Barth Syndrome") supported the development of the yeast model for Barth syndrome. This laid the groundwork for all of her subsequent studies of *tafazzin*-deficient yeast cells and helped her to obtain the preliminary data leading to an NIH R21 grant (2008-2010) entitled "Synthetic Lethal Interactions in Barth Syndrome."

From studies funded in part by the R21 grant, it was discovered that cardiolipin-deficient yeast cells exhibited defects in both iron homeostasis and metabolism, as well as defective import of proteins into mitochondria. BSF grants enabled Dr. Greenberg to explore the role of cardiolipin in these essential functions. To carry out studies to test this hypothesis, Dr. Greenberg was awarded an NIH grant (2014-2018) entitled "The Role of Cardiolipin in the TCA Cycle: Implications for Barth Syndrome." There is no question that BSF support has led directly to this NIH grant.

"I am very grateful for BSF support, which has enabled my research group to continue to develop and test hypotheses relevant to Barth syndrome. It is my fervent hope that our studies will contribute to our understanding of the pathology in Barth syndrome, and to the development of potential treatments for this disorder." ~ *Miriam L. Greenberg, PhD, Wayne State University, Detroit, MI*

Barth Syndrome GeneReviews®

Dr. Vernon

Barth syndrome now has a chapter in GeneReviews®, thanks to Hilary Vernon, MD, PhD (Assistant Professor, Genetic Medicine, Johns Hopkins University, Baltimore, MD) and several colleagues she brought in to help with this project! GeneReviews® are expert-authored, peer-reviewed disease descriptions ("chapters") presented in a standardized format and focused on clinically relevant and medically actionable information on the diagnosis, management, and genetic counseling of patients and families with specific inherited conditions.

Dr. Hilary Vernon and colleagues have provided a GeneReviews® article on Barth syndrome that will be very valuable not only for clinicians, but also for families. People with rare diseases suffer because little is known about their condition and even less is published for everyone to see. These book chapters provide an authoritative source for many genetic diseases, and now Barth syndrome is part of that collection. (This review can be found at http://www.ncbi.nlm.nih.gov/books/NBK247162/.)

Expansion of International Scientific and Medical Advisory Board

Dr. Tarnopolsky

BSF's international Scientific and Medical Advisory Board (SMAB) is a dedicated team of researchers and physicians who generously donate their time and expertise to our mission. Without them, we would not be able to review grant applications with multi-dimensional expertise or write medically-approved educational materials about Barth syndrome. These eminent scientists and physicians are central to our goals and our operation. BSF is incredibly pleased to introduce our new member, Mark Tarnopolsky, MD, PhD, FRCP(C) (Professor, Pediatric Medicine, McMaster University Medical Center, Ontario, Canada), who has agreed to serve for a four-year term. Dr. Tarnopolsky is an expert in mitochondrial and muscle disorders and is engaged in both clinical practice and research. (*See page 11 for SMAB roster.*)

SCIENCE & MEDICINE

Research Grant Program

With the completion of the 2014 Barth Syndrome Foundation (BSF) research grant cycle, 13 annual award cycles have committed a total of US $3.5 million to this important effort through 87 research grants to 50 principal investigators around the world. As with all BSF grant cycles, the projects submitted in October for the 2014 cycle that were accepted by BSF were actually awarded the following year. Thus, they are included in 2015 fiscal year expenses. BSF, with the advice of its international Scientific and Medical Advisory Board, and with support from international affiliates, awarded 8 research projects. BSF is very happy to be able to support the following grant recipients. (A complete list of all grant awardees can be found on BSF's website at www.barthsyndrome.org.)

	Valerian Kagan, PhD, Professor and Vice-Chairman, University of Pittsburgh, Pittsburgh, PA "Mechanism and role of cardiolipin oxidation and hydrolysis in Barth syndrome" Award—US $100,000 over 3-year period **Partial funding for this award was provided by Barth Syndrome Foundation of Canada*
	W. Todd Cade, PT, PhD, Associate Professor, Washington University School of Medicine, St. Louis, MO "Effects of resistance exercise training on cardiac, metabolic, and muscle function and quality of life in Barth syndrome: Part II" Award—US $45,313 plus $13,500 in travel funds over 1-year period **Funding for this award was provided by the Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome*
	Christina Pacak, PhD, Assistant Professor, University of Florida, Gainesville, FL "Correction of mitochondrial dysfunction in Barth syndrome" Award—US $100,000 over 3-year period **Partial funding for this award was provided by the Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome* **Partial funding for this award was provided by Association Barth France*
	Cynthia James, PhD, Research Associate, Johns Hopkins University, Baltimore, MD "How do women adapt to being a Barth syndrome carrier? A mixed methodological study of psychological adjustment and reproductive options" Award—US $48,563 over 2-year period
	John L. Jefferies, MD, MPH, Director of Advanced Heart Failure, Cincinnati Children's Medical Center, Cincinnati, OH "Assessment of quality of life, anxiety, and depression in Barth syndrome: Expanding the scope of comprehensive care" Award—US $28,749 over 2-year period **Partial funding for this award was provided by Barth Syndrome Trust*
	Adam Chicco, PhD, Associate Professor, Colorado State University, Fort Collins, CO "Translating murine *Taz* deficiency to human Barth syndrome: Focus on impaired lipid oxidation" Award—US $49,998 over 1-year period **Partial funding for this award was provided by Barth Syndrome Trust*
	Colin Phoon, MD, MPhil, Associate Professor, New York University School of Medicine, New York, NY "Novel antioxidant therapies in a mouse model of Barth syndrome" Award—US $50,000 over 2-year period **Funding for this award was provided by the Paula & Woody Varner Fund*
	Michael T. Chin, MD, PhD, Associate Professor, University of Washington, Seattle, WA "Enzyme replacement therapy in heart failure associated with *tafazzin* deficiency" Award—US $50,000 over 1-year period **Funding for this award was provided by the Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome*

Note: A new fund has been established in Will McCurdy's memory, the Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome. Contributions will be used by BSF exclusively for the development of therapies designed to prevent, alleviate, or eliminate the symptoms of Barth syndrome.

FINANCES

Your donations are precious to us, and without your contributions we really couldn't do what we do. These include ground-breaking research, support for families, not to mention our unique and highly-regarded conference. None of these programs could happen without your help. We are grateful to all those who respond willingly to our request for donations and are helping us get a little closer to our ultimate vision of a world in which Barth syndrome no longer causes suffering or loss of life.

You can feel confident when making a donation to BSF. Together, the staff and Board ensure that the endorsements of the Better Business Bureau Wise Giving Alliance and the National Health Council continue to be earned. The 20 Standards of Accountability and 43 Standards of Excellence, respectively, are applied to all we do.

Henry (age 2) with his cousin, Millie, at the 2014 Happy Heart Walk.

STATEMENT OF FINANCIAL POSITION

For year ended December 31, 2014 (with comparative totals for year ended December 31, 2013)

ASSETS

	12/31/2014	12/31/2013
Assets:		
Cash & cash equivalents	$ 679,419	$ 723,721
Investments	1,051,343	1,150,883
Accounts receivable	137,169	21,828
Prepaid expenses	6,394	12,118
Total assets	**$ 1,874,325**	**$ 1,908,550**

LIABILITIES AND NET ASSETS

	12/31/2014	12/31/2013
Liabilities:		
Accounts payable & accrued expenses	$ 16,400	$ 23,478
Grants payable	99,917	38,815
Total liabilities	**$ 116,317**	**$ 62,293**
Net Assets:		
Unrestricted	$ 530,698	$ 911,867
Temporarily restricted	1,227,310	934,390
Total net assets	**$ 1,758,008**	**$ 1,846,257**
Total liabilities & net assets	**$ 1,874,325**	**$ 1,908,550**

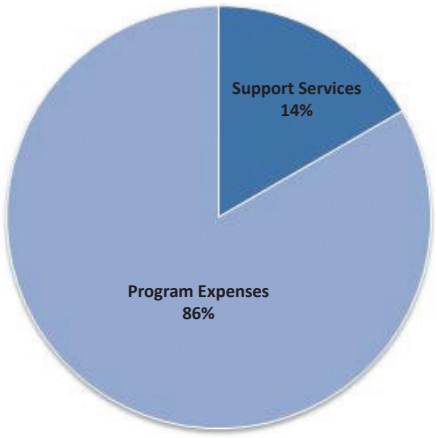
*See annual audit for notes and additional information.

STATEMENT OF ACTIVITIES

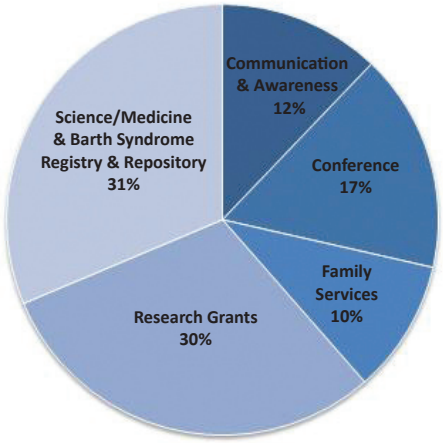
For year ended December 31, 2014 (with comparative totals for year ended December 31, 2013)

	Year Ended 12/31/14	Year Ended 12/31/13
PUBLIC SUPPORT AND OTHER REVENUES:		
Public Support:		
Contributions	$ 1,067,186	$ 824,480
Grant Income	35,060	-
	$ 1,102,246	**$ 824,480**
Investment Income	$ 4,925	$ 5,481
Unrealized Gain (Loss) on Investments	209	(6,099)
Total Public Support & Other Revenues	**$ 1,107,380**	**$ 823,862**
EXPENSES AND LOSSES:		
Program Services:		
Communication & Awareness	$ 124,666	$ 122,097
BSF Conference	168,161	839
Family Services	102,427	103,484
Barth Syndrome Registry & Repository	29,696	(46,845)
Research Grants	368,157	344,226
Research Grants Funded by BSF Affiliates	(59,080)	(45,948)
Science & Medicine	291,678	186,369
	$ 1,025,705	**$ 664,222**
Supporting Services:		
Management & General	$ 79,814	$ 82,489
Development & Fundraising	90,110	50,241
	$ 169,924	**$ 132,730**
Total Expense & Losses	**$ 1,195,629**	**$ 796,952**
CHANGE IN NET ASSETS	$ (88,249)	$ 26,910
NET ASSETS, beginning of year	$ 1,846,257	1,819,347
NET ASSETS, end of year	**$ 1,758,008**	**$ 1,846,257**

All Expenses



Breakdown of Program Expenses



Note: BSF's full 2014 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.

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Barth Trust of South Africa Jeannette Thorpe, *Chair* 49 Abelia Road Kloof, Pinetown, 3610 Natal, South Africa	**Association Barth France** Florence Mannes, *Chair* 12, rue Lalo 75116 Paris, France

2014 DONORS

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Dillon Foundation
Wilkins, Sue & Dr. Mike

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Wilkins, Joanne
Wilkins, John
Wilkins, Dr. Lee & Kristy
Wilkins, Muriel
Zank, Neil

SCIENCE & MEDICINE FUND

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Campbell, Debbie
Kirkland and Ellis Foundation
Olson, Richard & Sharon
Schoen, Christopher & Melissa
The Black Dog Private Foundation

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"The Barth Syndrome Foundation is very effective with the dollars that it raises. It's very smart in how it uses its still relatively scarce resources. I give to BSF because I respect what they do and I actually see what initially a small group of really committed people can do when they put their minds to it." ~ *Carroll, Donor*

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BSF Awarded Spot on 2014 Top-Rated List of Nonprofits from GreatNonprofits!

"BSF has changed our lives. When my 15 year old son was diagnosed with Barth syndrome, we were overwhelmed and lost. Through finding the Barth Syndrome Foundation, we were able to find specialists and information as to how to treat this extremely rare illness." *~ Michelle, Mother of Affected Individual, Ohio*

Luke (age 2) and Emily

Ashley (age 11) and Kai (age 13)

Ben (age 18) and David

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 all the boys and young men affected by Barth syndrome.

"The Barth Syndrome Foundation has not only saved my son's life through proper diagnosis of his disease, but they continue to fight for a cure with cutting edge research. 'Heart on a Chip' technology using Barth syndrome boys' own IPS cells and replacement enzyme therapies are being studied to hopefully find a cure someday. The boys, families, doctors and scientists are all truly amazing!" ~ *Bryan, Father of Affected Individual, Kansas*

With your help, we are moving forward together!

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

Member of the Genetic Alliance.

Member of the National Health Council, abiding by all 43 standards of excellence.

Accredited by the Better Business Bureau, meeting all accreditation standards.

Member of the Guide Star Exchange Program.

HEADQUARTERS

Barth Syndrome Foundation
PO Box 618 / Larchmont NY 10538 / Phone: 850-273-6974 / Email: bsfinfo@barthsyndrome.org

www.barthsyndrome.org

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