

Aiden (age 5)



(Photo courtesy of Aiden's family 2015)



# Dear BSF Friends,



When I reflect on our achievements in 2015, I feel proud and grateful. In this annual report, you'll read about how, after many years of hard work, Barth syndrome received our very own ICD-10 code (International Classification of Diseases Code). This major milestone may help us discover how many people are diagnosed with Barth syndrome.

In addition, you'll find how Shelley Bowen spread awareness through her powerful talk at the Innovations in Pediatric Heart Failure Symposium in San Diego, California. You'll also hear from Melanie, whose son has Barth syndrome, telling her personal story about what the Foundation means to her.

Lindsay Groff

As I was preparing this report, I received a call from a Barth mom. She said, "I just received your letter, and it was the most beautiful letter I have ever received." I had written this mom about a monthly donation, made in honor of her affected son, Kevin. The reason this letter had such an impact on her was because the donor was her other son, Matthew, who does not have Barth syndrome.

With a tear-filled voice, she shared with me how Barth syndrome affected not just Kevin, but their entire family. She explained that Matthew's world was rocked at three years old when Kevin was born, because Kevin immediately went into heart failure. When Kevin was 11, Matthew grabbed his sisters to comfort them as an emergency medical technician worked to bring Kevin back to life during cardiac arrest. She summed it up by saying, "Such is the life of a sibling of someone with Barth syndrome."

It turns out, Matthew didn't tell his mother that he arranged this monthly donation, and it wasn't her suggestion. Matthew did it because he wanted to honor Kevin and all of his "Barth brothers" around the world. I'm sure glad he did. His mother is not the only one that's proud and grateful; I am, too!

Matthew's gift reminded me once again what the power of giving has in our lives. While Barth syndrome can have a devastating effect on an entire family, so too, in an incredibly positive way, can giving.

Thank you to all of our donors, including our newest monthly donor, Matthew! Without your gifts, none of the wonderful progress that fills these pages would be possible. We simply couldn't do it without you.

With pride and gratitude,

*Lindsay B. Groff*

Lindsay B. Groff  
Executive Director

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Connor (age 5)



# Dear Friends,



Marc Sernel

I am pleased to report that 2015 was another strong year for the Barth Syndrome Foundation (BSF).

Thanks to the incredible generosity of our donors we have been able to expand our efforts while maintaining a strong balance sheet. We continue to raise the bar with our fundraising, with efforts to broaden the base of our donor pool resulting in nearly 1,000 donors including over 400 new donors last year. And our longtime donors were as generous as ever, with several huge donations helping to boost our overall fundraising to over \$3 million dollars for the year! Both personally and as Chairman of the Board of BSF, I am eternally grateful to our donors and everything they have contributed. While continued success in fundraising is far from guaranteed and will always be a challenge given the small size of our organization, our efforts in 2015 have helped to lay the foundation for BSF to

take the next steps in achieving our mission.

Beyond fundraising, BSF also enjoyed another good year in advancing awareness and research of Barth syndrome. As just one anecdote affirming our efforts, during a recent appointment my son's cardiologist raved about Shelley Bowen's great speech to a conference of pediatric cardiologists last December (see next page for more details). We also continue to make great progress with both foundational research and in moving toward possible clinical trials with not just one but several potential therapeutic candidates (see, e.g., page 8 for this year's research grants). All of the work done the past 15 years has put us on the cusp of game-changing breakthroughs, and I hope and expect to be writing to you in future annual reports about such breakthroughs.

But just as mountain climbers find the climbing becomes more difficult the higher you go, BSF will face new and greater challenges as we continue to strive for a treatment or cure for Barth syndrome. Taking the next steps from promising therapeutic possibilities to actual clinical trials to available treatments will require even more work, sacrifices, and resources than those we have expended to date. Thus, while I am proud of a great 2015 and thankful to all that contributed to our successes, I am also keenly aware of the challenges that lie ahead between us and our ultimate goals. I can assure you that BSF will not rest on its laurels and will continue to strive for the summit of our mission. Thank you all for your continued support in this journey.

*Marc Sernel*

Marc Sernel  
Chairman

## December 2015: Barth syndrome by the numbers

Known individuals living with Barth syndrome	187 in 26 countries
Number of individuals enrolled in Barth Syndrome Registry 2.0	54
Grant awards funded since BSF was established	95 totaling \$4 million
Percentage of BSF Staff and Board members who donated in 2015	100%

**"The Barth Syndrome Foundation is an incredible organization whose professional members — scientists, physicians, psychologists, nutritionists, physical therapists and others — freely interact with patients and their families, all focused on finding effective treatments for this rare disease. Though small, the Foundation manages to fund research (several projects every year!), host an biennial scientific and family conference that draws an international audience, and provide a vast support network for patients and families. The connectedness felt among all in the Foundation — from the sickest infants to the young men who have survived all challenges, to their parents and families, to those working towards a cure — is unlike anything I've witnessed in any other professional organization."** ~ Colin Steward, PhD, FRCP, FRCPCH, Bristol Royal Hospital for Children, England

# Awareness/Education/Support

## Extending Our Voice Globally

### Associazione Barth Italia

The Barth Syndrome Foundation (BSF) is pleased to announce our newest affiliate, Associazione Barth Italia, led by Paola Cazzaniga. Thanks to the work of several volunteers, we now have a formal presence in Italy. BSF is an international organization which relies heavily on its affiliates in different countries to help propel our shared mission. Our trusted partners show individuals with Barth syndrome and their families that, no matter where they are in the world, they have hope and a place in our global family.

The first meeting of Associazione Barth Italia took place on September 30, 2015, in conjunction with the International Congress on Cardiopilin. Affected families joined Barth experts to exchange information on issues concerning Barth syndrome. As part of the large 13<sup>th</sup> Euro Fed Lipid Congress held in Florence, Italy, several Barth syndrome researchers, including some of BSF's Scientific and Medical Advisory Board members, attended a satellite meeting that focused just on cardiopilin. BSF helped to support this meeting. In addition, some family members of the Italian affiliate of BSF were also present. Just like the BSF biennial conferences, mixing researchers with family members provided to be an enjoyable and rewarding experience for all.



Drs. Michael Schlame, Daniela Toniolo and Prof. Colin Steward at the 13<sup>th</sup> Euro Fed Lipid Congress

(Photo courtesy of Barth Italy 2015)

### Innovations in Pediatric Heart Failure Symposium

**“Physicians, surgeons, nurses, and practitioners of all backgrounds listened intently as Shelley described her struggle caring for boys with Barth syndrome. Shelley’s perspective was well received by all, and awareness for Barth syndrome was advanced by her insightful comments. She received a standing ovation and was approached by many members of the audience after her presentation.” ~ David Axelrod, MD, Pediatric Cardiology, Lucile Packard Children’s Hospital at Stanford, Palo Alto, CA**

We’ve come a long way since the inception of the Barth Syndrome Foundation (BSF) in 2000. We first began promoting awareness of Barth syndrome (BTHS) at professional meetings in February of 2002 in Orlando, FL at the Children’s Hospital of Philadelphia Cardiology meeting. During that meeting, we shared educational materials about BTHS to educate clinicians and families alike. Over the years, BSF has earned a reputation as a model organization in serving those who suffer with a rare disease.

Shelley Bowen, Director, Family Services & Awareness, was invited to speak before an audience of 256 pediatric heart failure healthcare providers at the Innovations of Heart Failure Symposium in San Diego, CA in December 2015. She provided insights on expanding knowledge about BTHS through research, the importance of educating families about the disease, and the difference being made by our organization. Shelley explained the foremost importance of receiving an accurate diagnosis that, ultimately, empowers a family to do something about the disease.



Innovations in Pediatric Heart Failure Symposium  
(Photo courtesy of Rakesh Singh, MD, MS 2015)

Shelley ended her talk by saying, *“Not having a diagnosis is like walking through the darkness with a nocturnal predator that can see you, but you can’t see it. You are helpless because you can’t predict where or when it might strike. Receiving a diagnosis is like being given night vision glasses. The predator is still there, but you can see it. You can learn how to skillfully anticipate what might happen next to prepare for an attack. Barth syndrome is that predator. If you (healthcare providers) will give our families the night vision glasses through a diagnosis and then encourage the families to contact us, we will be there for them.”*

*Thanks to our donors, our researchers, our boys and young men who are participating in research, and our programs, BSF fully intends to destroy that predator once and for all. No one can do this alone. We need doctors to diagnose. We need donors to invest in our mission. We need researchers to research, and we need those who have BTHS to participate in research. A diagnosis matters. Relationships matter. Differences matter. Most of all, the lives of those who have Barth syndrome matter.”*

# Awareness/Education/Support

## Major Milestone Reached by BSF: ICD Code E78.71 for Barth Syndrome

Sometimes the simplest of questions are the most difficult to answer. What are the incidence (newly diagnosed over span of time), prevalence (total population), morbidity (measure of illness) and mortality (measure of death) of Barth syndrome (BTHS)? It's complicated. We can provide de-identified metrics about those who have contacted us and enrolled in our Barth Syndrome Registry & Repository, but until recently that was the extent of our metrics. We had limited data to measure disease severity for those who had Barth syndrome on a global level. Nor did we know the number of deaths caused by Barth syndrome or how many people had been diagnosed with Barth syndrome worldwide.

From very early on, we at the Barth Syndrome Foundation (BSF) came to agree that ultimately one of the best ways to gain information about that unknown group was through the creation of an International Classification of Disease (ICD) code specifically for our disorder. Since BSF was established, it became one of our goals to have a distinct ICD code for Barth syndrome. While not infallible, an ICD code would provide a way to know just how many people were diagnosed with Barth syndrome.

The compliance deadline of the 43rd World Health Assembly by member states of the World Health Organization was October 1, 2015. **In this 10<sup>th</sup> version of ICD codes Barth syndrome was assigned a specific ICD code (E78.71).**

We have earned the reputation as the source of authority about Barth syndrome. Therefore, it is reasonable to receive inquiries about incidence, prevalence, morbidity, and mortality. With this specific code, we will now have a tool to begin to measure Barth syndrome health statistics in the broader population around the globe over the long term, in addition to the more detailed data we collect through the Barth Syndrome Registry & Repository.

This is a major accomplishment! We have strived to have a distinct ICD code since we were first formed in 2000. It wasn't possible to simply add a number for Barth syndrome. It was a huge, multi-country undertaking with complicated international bureaucratic processes. It took us 15 years and a great deal of multi-national teamwork for this goal to be achieved, but we did it!

## Mentoring our Community for Growth and Impact

Our mission is *"Saving lives through education, advances in treatments, and finding a cure for Barth syndrome,"* and we are able to extend our own work on this through alliances, regional outreach, and family gatherings. We educate healthcare providers to facilitate timely diagnosis and inform doctors how Barth Syndrome Foundation can make a difference for their patients. We motivate researchers by introducing them to the people who will benefit from their work. We also increase the willingness of regional doctors and researchers to promote awareness about Barth syndrome. Once again, our regional gatherings in 2015 were a resounding success.

In 2015, during the Mid-Western Family Outreaches, families visited regional and national landmarks together, benefited from the support of each other's company, and shared the joys of parenting together. Boys and girls alike relished watching and learning expert tree climbing tips from dad, Tim, and fancy fencing footwork by dad, Ned. The instant bond among the children who had never met someone like them was palpable when families gathered in Boston during the New England Family Outreach organized by Susan and Anne, Barth family members. There was no shortage of fun and fellowship during any of these gatherings.

During the Mid-Western Family Outreaches, Shelley and Barth family members, Brie, Erin, and John visited with faculty members in molecular genetic laboratories and with pediatric subspecialists in Cincinnati, Omaha, Kansas City, and Overland Park to promote awareness about Barth syndrome. These visits included educational sessions and research updates and were recorded and uploaded to our website. During St. Louis, Shelley met one of the healthy control volunteers in Dr. Cade's clinical research investigation. Dr. Reeds (co-investigator in Dr. Cade's study) fondly spoke about the boys he has met with Barth syndrome. The dedication of these researchers isn't left "at the office." It carries over into their private lives and families. Dr. Reeds' eight-year-old son told his father, "I want to help boys with Barth syndrome." Shelley also visited with a 55 year old man with Barth syndrome and his sisters who couldn't go to the family outreach.



[L-R] Walker (age 27) and John (age 32) (Photo courtesy of BSF 2015)



[R-L] Bob (age 55) and his sisters (Photo courtesy of Bob's family 2015)

# Family Services

**“Thoughts of my brother’s passing overtook my mind. I remember having tears of fearfulness day after day, rather than tears of joy that a new baby usually brings” ~ Melanie , Mother of Aiden, Australia**

*(Photo courtesy of Melanie 2016)*



Aiden (age 5)

## Meet Aiden

Barth syndrome has meant so many things to me over the years. My brother, Craig, passed away in 1970 when he was only four months old. Admittedly, not much was spoken of Craig throughout my childhood. His birthday came and went each year, followed closely with the anniversary of his death, yet silence was often the way my parents dealt with this time of the year. This was not denial, but more an unspeakable deep hurt... a deep void that my parents felt and continue to feel with each current day. A void that only a parent who has lost a child can possibly understand.

We learned more about my brother’s condition in 1997. This was when my entire family was genetically tested for the Barth syndrome (BTHS) gene. The results identified my grandmother, my mum, and myself as being carriers. At the time, I was 19 years old, and these results had little, if any, impact on me. I was offered counselling to discuss any concerns or thoughts I may have been experiencing. However, becoming a mother at that stage was not a reality, and therefore the counselling meant little to me.

What was most significant from the family’s genetic results was discovering that my Uncle Greg (mum’s brother) had the BTHS gene. He was 45 years old at the time, and today is in his mid-60s! His main symptom is cardiomyopathy, and to this day he has never been hospitalised by Barth-related illness. He is an amazing ‘Barth Story’ and continues to live life to his fullest!

Life continued, and it wasn’t until 2008 when the impact of being a carrier became a reality, a very scary reality. My husband, Luke, and I fell pregnant with our first child. Being a confirmed carrier, I had a test performed at 12 weeks. This first test came back negative for Barth syndrome, and Sebastian was born in March 2009. In late 2010, we were expecting our second child, and had the same test performed. This test result was positive, and our “Barth Boy,” Aiden, was born in May 2011. We went through this same process in 2013 when pregnant with our third (and last!) child. Max was born in January 2014 and is not affected.

The arrival of any baby, regardless of health, is a blur of excitement, emotion and questions. Aiden’s delivery was quite intense, with many doctors and specialists in attendance due to his prenatal diagnosis of Barth syndrome. Because of Aiden’s better-than-expected condition, we were able to take him home when he was ten days old. I was so excited to finally be able to bring him home, yet so frightened about what could go wrong. Thoughts of my brother’s passing overtook my mind. I remember having tears of fearfulness day after day, rather than tears of joy that a new baby usually brings.

After being home for only one week, reality struck. Aiden was re-admitted into the cardiac intensive care ward. He was in severe heart failure. We quickly reached out to the Barth Syndrome Foundation (BSF). It was then when my fear turned to hope. I was able to start piecing together parts of the puzzle that is Barth syndrome. It became apparent that this very complex and deceptive condition has a unique, loving, and supportive community. Luke and I were received with warm welcomes from voices all around the world, and the Listserv quickly became my most visited on-line site. They were sharing their stories and offering guidance based on experiences and challenges they have faced with their own Barth sons. During these first few contacts, we were persuaded to attend the Foundation’s conference.

The benefit that BSF brings to my family is indescribable. The awareness of Barth syndrome within the Australian medical sector is quite limited, and when meeting a new doctor for the first time I am often greeted with, “I’ve never actually heard of Barth syndrome before.” It’s with pride that I discuss the work of the Foundation with Australian doctors who are new to treating Barth syndrome. I often praise BSF’s advocacy work and research efforts, and equally as important, the efforts of our donors worldwide.

**Aiden will celebrate his fifth birthday in May 2016. On this day, we celebrate more than his birthday. We celebrate my brother. We celebrate family love. We celebrate family support. We celebrate the Barth Syndrome Foundation. And, we celebrate our donors.**



# Science & Medicine

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



Dr. William Pu

Barth syndrome researcher, William T. Pu, MD, Boston Children’s Hospital, Boston, MA, recently has been awarded an R01 grant from the National Institutes of Health entitled, “**Understanding mitochondrial regulation of cardiac development and function through studies of Barth syndrome**”. (Project #: 1R01HL128694-01)

Barth syndrome researcher, Michael Schlame, MD, New York University School of Medicine, New York, NY, also has been awarded an R01 grant from the National Institutes of Health entitled, “**Abberant cardiolipin dynamics in Barth syndrome.**” (Project #: 1R01GM115593-01)



Dr. Michael Schlame

This is the second RO1 award for Barth syndrome-related research for Dr. Schlame, who is also chairman of BSF’s Scientific & Medical Advisory Board (SMAB). For Dr.

Pu, who is also a member of the SMAB, this RO1 builds on the work that the Barth Syndrome Foundation (BSF) has helped to support through its Research Grant Program. BSF is very grateful to have these two extraordinary researchers and SMAB members helping us accomplish our goal.

## Expansion of BSF International Scientific and Medical Advisory Board

In the 15 years since the first Barth Family Meeting in 2000 and the subsequent formation of the Barth Syndrome Foundation (BSF), the growth and accomplishments of the Foundation have been outstanding. One of the greatest accomplishments has been the development of the international Scientific and Medical Advisory Board (SMAB) which was established by Kate McCurdy, former BSF board member and now *Emerita* member of the SMAB. The SMAB’s membership is made up of expert doctors, researchers, and scientists in the various areas where Barth syndrome manifests itself. They help develop new research to learn more about this disorder and to lead toward possible treatments by reviewing all of the research grant applications and providing advice to the Board on where to channel the precious research funds. In order to keep the SMAB fresh and dynamic while moving forward, new members with their unique ideas, perceptions, and expertise are occasionally added to strengthen and grow the SMAB. BSF is incredibly pleased to introduce our new members, Dr. John Jefferies of Cincinnati Children’s Hospital Medical Center, and Dr. Hilary Vernon of Johns Hopkins University and the Kennedy Krieger Institute.



Dr. John Jefferies

**Dr. John Jefferies, MD, MPH** is a Professor of Pediatric Cardiology and Adult Cardiovascular Diseases and the Director of Advanced Heart Failure/Cardiomyopathy within the Heart Institute at Cincinnati Children’s Hospital Medical Center. He completed his combined Pediatric and Adult Cardiology training at the Baylor College of Medicine in Houston, Texas at the Texas Children’s Hospital and the Texas Heart Institute.

His current research interests include heritable causes of vascular disease, novel drug therapies for advanced heart failure, novel gene discovery in cardiomyopathy, characterization and management of left ventricular noncompaction (LVNC), and early diagnosis and management of chemotherapy induced cardiotoxicity.



Dr. Hilary Vernon

**Dr. Hilary Vernon, MD, PhD** is an Assistant Professor of Genetic Medicine at the McKusick-Nathans Institute of Genetic Medicine at Johns Hopkins University and at the Kennedy Krieger Institute (KKI) where she also is the Director of the Barth Syndrome Interdisciplinary Clinic. In addition, Dr. Vernon serves on the Maryland State Advisory Council on Hereditary and Congenital Disorders. She earned her MD and PhD at Rutgers University and completed residencies in Genetics and Pediatrics at Johns Hopkins University and a fellowship in Clinical Laboratory Biochemical Genetics at Johns Hopkins University. Dr. Vernon is board certified in Pediatrics, Clinical Genetics, and Clinical Laboratory Biochemical Genetics.





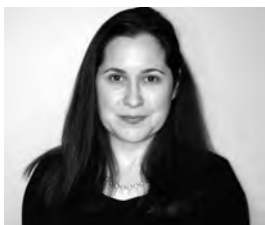

Her main areas of research include understanding intermediary metabolism in Barth syndrome and in disorders of branch chain amino acid metabolism. Dr. Vernon knows many of the Barth guys well because she sees them as the metabolic expert at the Barth Syndrome Clinic that is held four times a year at KKI. She is collecting longitudinal data that will increase the understanding of this disorder and may be helpful as we enter our new phase of clinical trials. (See page 11 for SMAB roster.)

(Photos courtesy of Drs. Pu, Schlame, Jefferies & Vernon 2015)

# Science & Medicine

## Research Grant Program

With the completion of the 2015 Barth Syndrome Foundation (BSF) Research Grant Cycle, 14 annual award cycles have committed a total of US \$4 million to this important effort through 95 research grants to 56 principal investigators around the world. As with all BSF grant cycles, the projects from the 2015 cycle that were accepted by BSF were actually awarded the following year, thus being included in 2016 fiscal year expenses. BSF, with the advice of its international Scientific and Medical Advisory Board, and with support from international affiliates, awarded six research projects. BSF is very happy to be able to support the following grant recipients:

	<p><b>Eric Ortlund, PhD</b>, Associate Professor, Emory University, Atlanta, GA</p> <p><i>“Structural studies of human tafazzin”</i></p> <p>Award—a maximum of US \$50,000 over 1-year period</p>
	<p><b>George Schweitzer, PhD</b>, Postdoctoral Research Associate, Washington University School of Medicine, St. Louis, MO</p> <p><i>“Metabolic adaption in Barth syndrome”</i></p> <p>Award—US \$50,000 over 1-year period</p>
	<p><b>Yuguang (Roger) Shi, PhD</b>, Professor, University of Texas Health Sciences Center in San Antonio, San Antonio, TX</p> <p><i>“Molecular mechanisms underlying a causative role ALCAT1 in the pathogenesis of Barth syndrome”</i></p> <p>Award—US \$100,000 over 3-year period</p>
	<p><b>Miriam Greenberg, PhD</b>, Professor, Wayne State University, Detroit, MI</p> <p><i>“Cardiolipin is required for mitochondrial protein processing”</i></p> <p>Award—US \$50,000 over 1-year period</p>
	<p><b>Robin Duncan</b>, Assistant Professor, University of Waterloo, Waterloo, Ontario, Canada</p> <p><i>“A new enzyme and pathway in cardiolipin synthesis”</i></p> <p>Award—a maximum of US \$50,000 over 2-year period</p> <p><i>*Partial funding for this award was provided by Barth Syndrome Foundation of Canada</i></p>
	<p><b>Doron Rapaport, PhD</b>, Professor, University of Tuebingen, Tuebingen, Bavaria, Germany</p> <p><i>“Use of high throughput screens in yeast to investigate the pathomechanism of Barth syndrome”</i></p> <p>Award—a maximum of US \$50,000 over 2-year period</p> <p><i>*Partial funding for this award was provided by Association Barth France</i></p>

A complete list of all grant awardees can be found on BSF's website at [www.barthsyndrome.org](http://www.barthsyndrome.org).

*(Photos courtesy of grant recipients 2016)*



# Finances

Thanks to **YOUR** incredible generosity, we ended 2015 with a record-breaking total of donations. We raised over three million dollars, \$3,147,381 to be exact! This is huge news. We will use every single dollar raised to fight our enemy, Barth syndrome.

By now, you've likely read all about our achievements in 2015. None of this work would have happened without your help. We are grateful to all those who respond readily to our request for donations. You 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 endorsement of the Better Business Bureau Wise Giving Alliance and the National Health Council continues to be earned. The 20 Standards of Accountability and 43 Standards of Excellence, respectively, are applied to all we do. We have also earned a top rating from Great Nonprofits.



Brayden (age 6)  
(Photo courtesy of Brayden's family 2015)

## Statement of Financial Position

For year ended December 31, 2015 (with comparative totals for year ended December 31, 2014)

### Assets

	12/31/2015	12/31/2014
<b>Assets:</b>		
Cash & cash equivalents	\$ 1,592,360	\$ 679,419
Investments	2,302,699	1,051,343
Accounts receivable	2,352	137,169
Prepaid expenses	16,495	6,394
<b>Total assets</b>	<b>\$ 3,913,906</b>	<b>\$ 1,874,325</b>

### Liabilities and Net Assets

	12/31/2015	12/31/2014
<b>Liabilities:</b>		
Accounts payable & accrued expenses	\$ 16,726	\$ 16,400
Grants payable	224,101	99,917
<b>Total liabilities</b>	<b>\$ 240,827</b>	<b>\$ 116,317</b>

### NET ASSETS:

Unrestricted	\$ 700,727	\$ 530,698
Temporarily restricted	2,972,352	1,227,310
<b>Total net assets</b>	<b>\$ 3,673,079</b>	<b>\$ 1,758,008</b>
<b>Total liabilities &amp; net assets</b>	<b>\$ 3,913,906</b>	<b>\$ 1,874,325</b>

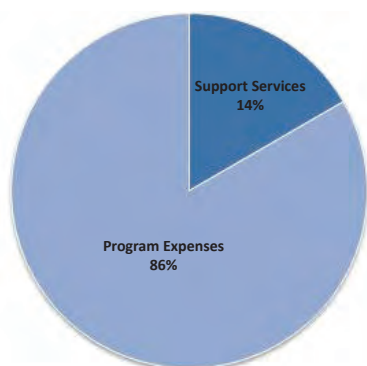
\*See annual audit for notes and additional information

## Statement of Activities

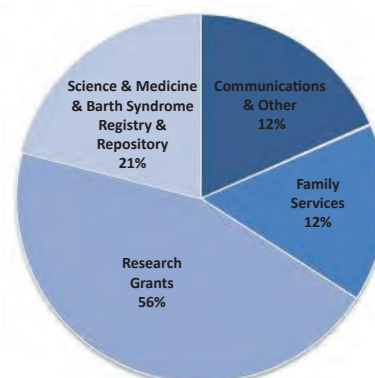
For year ended December 31, 2015 (with comparative totals for year ended December 31, 2014)

	Year Ended 12/31/15	Year Ended 12/31/14
<b>PUBLIC SUPPORT AND OTHER REVENUES:</b>		
Public Support:		
Contributions	\$ 3,074,346	\$ 1,067,186
Grant Income	64,475	35,060
Interest Income	9,671	4,925
Realized Gain (Loss) on Sale of Stock	16,961	(74)
Unrealized Gain (Loss) on Investments	(18,072)	283
<b>Total Public Support &amp; Other Revenues</b>	<b>\$ 3,147,381</b>	<b>\$ 1,107,380</b>
<b>EXPENSES AND LOSSES:</b>		
Program Services:		
Communications & Other	\$ 121,864	\$ 124,666
BSF Conference	30	168,161
Family Services	126,542	102,427
Barth Syndrome Registry & Repository	23,013	29,696
Research Grants	625,381	368,157
Research Grants Funded Directly by BSF Affiliates	(34,917)	(59,080)
Science & Medicine	197,725	291,678
	<b>\$ 1,059,638</b>	<b>\$ 1,025,705</b>
Supporting Services:		
Management & General	\$ 86,987	\$ 79,814
Development & Fundraising	85,685	90,110
	<b>\$ 172,672</b>	<b>\$ 169,924</b>
<b>Total Expense &amp; Losses</b>	<b>\$ 1,232,310</b>	<b>\$ 1,195,629</b>
<b>CHANGE IN NET ASSETS</b>	<b>\$1,915,071</b>	<b>\$ (88,249)</b>
<b>NET ASSETS, beginning of year</b>	<b>1,758,008</b>	<b>1,846,257</b>
<b>NET ASSETS, end of year</b>	<b>\$3,673,079</b>	<b>\$ 1,758,008</b>

**All Expenses**



**Breakdown of Program Expenses**



Note: BSF's full 2015 audited financials are available on our website at [www.barthsyndrome.org](http://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 2005 Palmer Avenue #1033, Larchmont, NY 10538			
BOARD OF DIRECTORS (as of April 2015)			
Marcus E. Sernel, <i>Chairman</i>	Susan A. McCormack, Secretary	Kevin Woodward, Board Member	
David Axelrod, MD, Board Member	Susan S. Osnos, Board Member	Lindsay B. Groff, <i>ex-officio</i> , Executive Director	
Matthew Blumenthal, Board Member	Catharine L. Ritter, Board Member	Stephen B. McCurdy, <i>Chairman Emeritus</i>	
Randy Buddemeyer, Treasurer	John Wilkins, Board Member		
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Lindsay B. Groff Executive Director	Shelley Bowen, Director Family Services & Awareness	Lynda M. Sedefian Executive Assistant	Matthew J. Toth, PhD Science Director
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## BSF Awarded Spot on 2015 Top-Rated List of Nonprofits from GreatNonprofits!



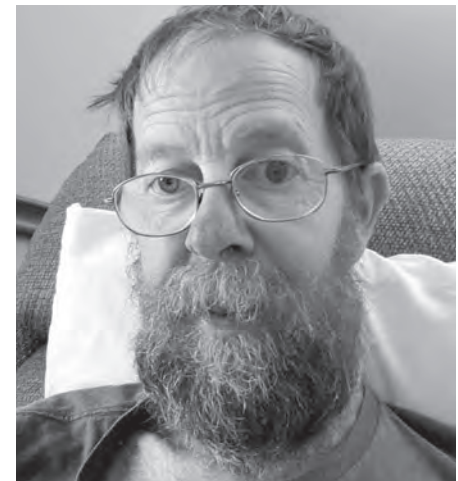
**“BSF is truly an amazing organization. They are a lifeline to families and individuals affected by Barth Syndrome. The wealth of knowledge and information, compassion and understanding, friendship and hope, that comes from being a part of an active, professional and caring foundation is beyond words.” ~ Ned, Parent of Affected Individual**



Eli (age 2)



Greyson (age 8)



Bob (age 55)

(Photos courtesy of Eli, Greyson and Bob's families 2015)



## 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.



Christopher (age 7)

*(Photo courtesy of Christopher's family 2015)*

**"We are so glad that we found BSF! We were warmly welcomed into what is commonly referred to as a family. I see why the BSF is described as such and is composed of families, physicians, scientists, donors, and volunteers around the world. This overwhelming, mind boggling disease has a group of warm, caring, compassionate and INFORMED people. It is such a reassuring feeling to know there are others who have been exactly where we have been." ~ Kristi, Parent of Christopher, Mississippi**

**With your help, we are moving forward together!**



(Photo courtesy of BSF 2016)

Clint (age 16) & Dr. Matt Toth

## 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

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