



BARTH SYNDROME FOUNDATION ANNUAL REPORT 2017



Branislav, Jr. (age 4 weeks)



Branislav, Jr. (age 5 months)

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

(Photos courtesy of Branislav, Sr. 2017)

ABOUT THE BARTH SYNDROME FOUNDATION

Barth syndrome (BTHS; OMIM #302060) is a rare, life-threatening genetic disorder primarily affecting males. It is caused by a mutation in the *tafazzin* gene (*TAZ*, also called G4.5), resulting in an inborn error of phospholipid metabolism.

The Barth Syndrome Foundation is the only organization dedicated to saving lives around the world through education, advances in treatments, and finding a cure for Barth syndrome.

- We work tirelessly to advance research, serve as a resource for families and healthcare providers, and raise public awareness. We pursue the most innovative research and make sure that it receives proper funding.
- We create an informed public and educated patient community to increase early diagnosis and ensure life-saving treatment.
- We provide relentless support to families, caregivers, and healthcare providers.
- We will not rest until we have achieved victory — a world in which Barth syndrome no longer causes suffering or loss of life.

Visit barthsyndrome.org to learn more.

December 2017: Barth syndrome by the numbers

Known individuals living with Barth syndrome **213** in **30** countries

Grant awards funded since BSF was established **104** totaling **\$4.5 million**

Percentage of BSF Staff and Board members who donated in 2017 **100%**

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Ty (age 4)



Photo courtesy of Tracy 2017



Susan McCormack

Dear Friends,

This letter marks my transition to the position of Chair of the Barth Syndrome Foundation. I am humbled by this honor and want to thank our previous Chair, Marc Sernel, for his numerous years of service and dedication to our group.

I am pleased to report that 2017 was another dynamic and productive year for BSF. Your generous donations continue to advance our mission:

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

In the following pages, you will find the myriad ways in which your donations benefit Barth syndrome patients and families throughout the world.

- In 2017, BSF reached a milestone when we awarded our 100th research grant. To date, the Foundation has awarded grants totaling \$4.5 million. This dollar amount, however, pales in comparison to the volume of follow-on funding that has been generated from our “seed donations.” For example, on page 7, you will read that Dr. William Pu was recently awarded an R01 grant from the National Heart, Lung, and Blood Institute that effectively quintupled BSF’s initial donation for his research.
- The year 2017 marked the Barth syndrome community’s entrance into the realm of clinical trials. In April, BSF began involvement in its first pharmaceutical clinical trial, called TAZPOWER. This trial, for the compound Elamipretide, is expected to be completed within the next year. A second clinical trial – the CARDIOMAN study for the pharmaceutical Bezafibrate – is anticipated to begin in the United Kingdom soon (see page 6).
- Shelley Bowen’s tireless efforts to spread awareness and to educate Barth syndrome patients and their families are continuing to enrich lives. This is described eloquently by the father of Branslav, Jr., on page 4.

Financially, Barth Syndrome Foundation remains healthy, finishing the year with a modest surplus. Our net assets of just over \$3 million place the Foundation in the vital position of being prepared to fund potentially costly future treatment advances envisioned in our near future (see pages 9-10).

In November of 2017, BSF’s Executive Director, Lindsay Groff, resigned her position. However, the Foundation’s work has continued unabated due to the strength of its staff (Shelley Bowen, Matt Toth, and Lynda Sedefian) and board during our search for BSF’s next Executive Director.

We look forward to 2018 with great hope for continued progress toward enriching the lives of our families, achieving breakthroughs in the scientific and medical arenas, and managing transition within the organization. Thank you all for your commitment to our mission.

Susan McCormack

Susan McCormack
Chair

“As mother to a son with Barth syndrome, this foundation is a total life line, and I mean that literally! This condition is rare and complex, so to know that there is a forum to share wisdom and expertise not only from other parents but also with medical and scientific specialists and experts in their fields and from around the world is nothing short of remarkable. You can’t imagine how supportive that is and how there can never be enough thanks given!” ~ Anonymous

Awareness/Education/Family Services

The first words of Barth Syndrome Foundation's (BSF) mission statement are: "Saving lives through education..." and BSF's first stated goal is "To ensure that everyone with Barth syndrome is quickly and accurately diagnosed." These two endeavors go hand in hand. To achieve them, BSF expends a portion of its resources on the two key areas of Communications and Family Services. The monies spent in these areas are critical, as is evident in the story of little Branislav, Jr.

"The results of genetic tests were ready one month after the first heart failure, and Barth syndrome was confirmed. ... I contacted the Barth Syndrome Foundation, and thanks to Shelley Bowen, we gained contact with other families and could start to learn how to live with all the complicated health problems." ~ Branislav, Father of Affected Individual, Slovakia



Branislav, Jr. (age 9 months)

Meet Branislav, Jr.

A year ago, we were a family with two daughters and had celebrated 10 years of marriage, but then a big surprise came. My wife was pregnant. Our happiness became greater when we found out we were going to have a son. Everything was fine, and Branislav Jr. was born on May 29, 2017. After three weeks at home, my wife said, "Look at his colour." When I saw the purple-gray skin of our son, I took him to the pediatric ambulatory care immediately. The ride took me about three minutes, as we needed a doctor to help him with oxygen. After one hour of resuscitation, he was taken to the ER at the Children's Hospital in Bratislava, Slovakia, about 100 km from where we live.

I told my wife only parts of the story right away, as I didn't want to scare her too much. We had to wait about three hours to see Branislav, and then the biggest shock came. The doctors told us that he had little hope of living. But sometimes miracles happen, and, in seven days, he could breathe without ventilation. We "came up for air" briefly after this strange week, but we were "drowned" again only three days later when our son's heart failed again. At that point, children's cardiology admitted him.

Back then, Dr. Kunovský said something about Barth syndrome. My wife called me from the hospital about it. I tried to google it, but I didn't understand her at first and had typed "Bart syndrome" (without the H). I didn't believe what I read, because Branislav was born with skin. This misunderstanding was explained, and I started studying the "right syndrome."

Unfortunately, our son's heart failed again in two weeks due to bad cardiomyopathy, and we thought we had no hope, with another resuscitation that took seven minutes. The results of genetic tests arrived at almost the same time, and the diagnosis of Barth syndrome (BTHS) was real for us. It was then that we had the first interviews about heart transplantation, and we learned about a collaboration between the Pediatric Cardiac Center in Bratislava and Children's Hospital in Philadelphia, USA. The most complicated and rarest cases are presented and consulted with American experts through video conference hosted by the U.S. Embassy in Bratislava. Later the U.S. Embassy donated equipment to the Bratislava Pediatric Cardiac Center so that the Center's doctors are now able to consult directly with international experts and better treat their acute patients.

The results of genetic tests were ready one month after Branislav's first episode of heart failure, and BTHS was confirmed. Unfortunately, geneticist Laszlo Kovacs died from a heart attack before our son's diagnosis was finalized. I contacted the Barth Syndrome Foundation (BSF), and thanks to Shelley Bowen (Director, BSF Family Services & Awareness), we gained contact with other families and could start to learn how to live with all the complicated health problems. We were surprised how many people offered help, which we needed.

Two months later, both our daughters, my wife and my wife's mother were confirmed as carriers of BTHS, so we have to take our son's illness as preparation for our future grandchildren. Branislav is at home now, and he makes us proud parents of very rare child. As we enjoy every little thing, other things which were important in the past became irrelevant, and long-term plans don't exist for us it seems. We are thankful to all family members, friends and the Barth Syndrome Foundation for contact with people sharing the same fate, who help us to live with this health condition. *(Photo courtesy of Branislav, Sr. 2017)*

Awareness/Education/Family Services

Indianapolis Family Gathering

The Barth Syndrome Foundation (BSF) Outreach Program was developed to foster relationships with our regional families through informal gatherings in those years when we do not have an international conference. During these get togethers, families share what they've learned about caring for those with Barth syndrome, imparting vital information to one another that improves care. This type of gathering enables BSF to maintain a sense of community among our members. It is also our intention to encourage a sense of ownership of BSF.

In July 2017, Tiffini hosted a family outreach where families from around the midwest convened. The families initially gathered in downtown Indianapolis, one block from Lucas Oil Stadium. The first night offered an opportunity for the families to catch up on everyone's adventures from the past year, and they watched movies until early morning. The next afternoon the families ventured out to the Indianapolis Zoo. The orangutans were a huge hit with all of the kids as well as the adults. That evening they grilled out, and the kids played baseball and ran around the playground. Sunday morning everyone enjoyed their breakfast together before saying their goodbyes. Overall, it was a relaxing weekend, and most importantly, everyone had a wonderful time catching up with each other and sharing experiences and knowledge about Barth syndrome, as always.



Families helped educate and support each other at BSF's Indianapolis Family Outreach (Photos courtesy of Tiffini 2017)

Professor Colin Steward Receives Esteemed 2017 International RARE Champion of Hope Award for Outstanding Achievements in the Medical Care and Treatment of Barth Syndrome



Prof. Colin Steward

Colin Steward, PhD, FRCP, FRCPC, Consultant in Bone Marrow Transplantation, Royal Hospital for Children; Reader in Stem Cell Transplantation, University of Bristol, Bristol, England, United Kingdom, attended the 2017 RARE Patient Advocacy Summit and RARE Tribute to Champions of Hope series of events held on September 14–16, 2017 in Irvine, California, where he was honored at the RARE Champion of Hope Award Ceremony as well as the Tribute on Saturday, September 16, 2017.

Prof. Steward has dedicated a huge part of his life to helping families with Barth syndrome lead better quality lives, looking further than medicine to see the whole person and to put the person at the center of his medical care. He is known, respected, and admired by so many within our international community. He is a powerful voice for our rare condition and for providing better medical care today with the hope of a successful treatment for the future.

One of Prof. Steward's current pursuits is an exciting clinical trial of a drug therapy for Barth syndrome in the United Kingdom, the CARDIOMAN trial. His work in creating this clinical trial provides a sense of hope to families, as he continues to search for ways to improve the lives of those affected by Barth syndrome.

Prof. Steward is a senior member of the international Scientific and Medical Advisory Board of the Barth Syndrome Foundation. He has co-authored five publications about Barth syndrome, including a pivotal review of this disease. He acts as an ambassador for the disease, speaking at many scientific and medical conferences around the world. (Photo courtesy of Amanda Clark 2016)

Science & Medicine

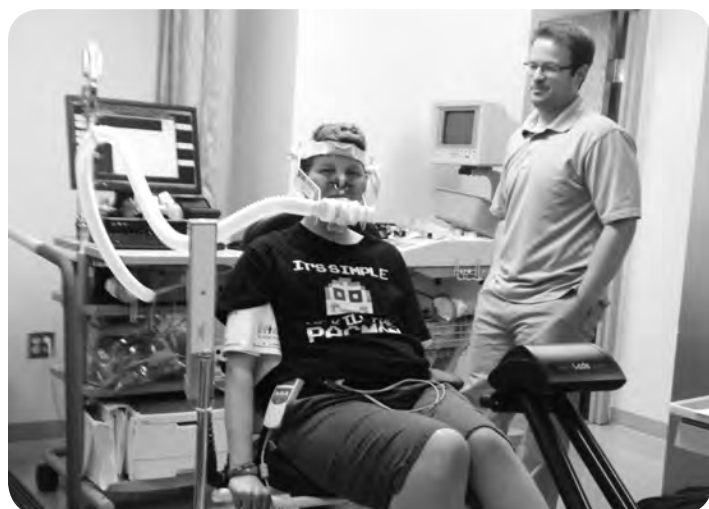
Clinical Trials ~ Our New Exciting Reality

The research that the Barth Syndrome Foundation (BSF) has supported over the years through its grant program, through its conference clinics that members have participated in, and through the scientific-medical discussions/debates that take place at the conferences and beyond, have all contributed to getting us to where we are now. BSF is in a position to finally reap the rewards of what it has carefully sown and cultivated over the years. The major medical research and pharmaceutical approval agencies of the US government are now explicitly encouraging and endorsing what BSF has been doing since its inception — fostering a vibrant and caring scientific-medical-patient community to help our members, and others like them. We are united in a struggle to lessen the suffering of not only our own members, but that of others with similar diseases.

In April of 2017, the company Stealth Biotherapeutics initiated a clinical trial with Barth syndrome individuals testing their lead compound Elamipretide — the TAZPOWER study. Barth syndrome will soon embark on another pharmaceutical clinical trial using the pharmaceutical Bezafibrate which will take place in the United Kingdom — the CARDIOMAN study. We anticipate a third trial starting soon that involves gene therapy, which is very exciting due to its revolutionary approach for treating human disease. Clinical trials of other therapies also are being planned, as we want to keep up the therapeutic assault on this cruel disease. BSF is very fortunate and blessed to have researchers, clinicians, and members who have worked hard and struggled to be where we are now — enrolling volunteers to test specific treatments for Barth syndrome.

A clinical trial is an experiment on humans that tests the usefulness of a particular therapy in a scientific way. All clinical trials benefit from what has come before, and volunteering for any clinical trial has great value. No one can predict whether one therapy or another (or a combination of therapies) will be useful, but the process of performing any clinical trial gives the healthcare and research community a great deal of information about the disease under study. We need those who are able to step up and volunteer as much as they can. These volunteers not only have the potential to help themselves, but they also will help fellow Barth individuals who cannot participate, and they may help other people afflicted with similar serious diseases.

In 2017, Dr. Matt Toth, BSF Science Director, attended several meetings at the major funding and drug approval arms of the US government — the National Institutes of Health (NIH) and the Food and Drug Administration (FDA), respectively. There is new thinking taking hold at both of these organizations that heralds a renaissance in how advances in healthcare are made. A remarkable consortium of academic, industrial, and patient advocate organizations is focusing their efforts on the patient and on rare disease sufferers in particular. The NCATS division (National Center for Advancing Translational Science) of the NIH has put together a “toolkit” to do the very things BSF has been doing for years, and it describes what we should be doing (and are) in this era of clinical trials for Barth syndrome. No rare disease will be left behind by NCATS. Patient advocate organizations like BSF are an integral and essential part of this consortium. BSF is made up of the only people who can volunteer to test these new drugs/treatments for Barth syndrome in the clinical trials.



(L-R) Nick (age 20) and Devin (age 13) help advance potential treatments by participating in Dr. Todd Cade's exercise study
(Photos courtesy of Michaela and Nicole 2017)

Science & Medicine

BSF Researcher Awarded R01 Grant from the National Institute of General Medical Sciences



Dr. William T. Pu

Once again, seed money granted by Barth Syndrome Foundation (BSF) has led to follow-on funding, effectively quintupling BSF's initial research dollars. Barth syndrome researcher, William T. Pu, MD, Professor of Pediatrics, Harvard Medical School; Department of Cardiology, Boston Children's Hospital; Principal Faculty, Harvard Stem Cell Institute, Boston, MA, was awarded an R01 grant from the National Heart, Lung, and Blood Institute for his proposal entitled "Understanding mitochondrial regulation of cardiac development and function through studies of Barth syndrome". This grant will enable Dr. Pu to continue the work that he began with initial funding from the Barth Syndrome Foundation. This study will provide fundamental information on cardiolipin and mitochondrial function in heart development and heart disease. The studies will have direct relevance to the pathogenesis of Barth syndrome as well as more common cardiovascular diseases and will inform development of targeted therapy for Barth syndrome.

Dr. Pu has been awarded the following four research grants from BSF entitled "Reactive oxygen species and mitochondrial dynamics in the pathogenesis of Barth syndrome" (2013); "Maturation of Barth syndrome models for clinical translation" (2012); "Using induced pluripotent stem cells and modified RNAs to model and correct Barth syndrome" (2011); and "Analysis of metabolic abnormalities in TAZ-deficient cardiomyocytes" (2009). Dr. Pu also serves on BSF's international Scientific and Medical Advisory Board. *(Photo courtesy of Amanda Clark 2016)*

Research Grant Program

With the completion of the 2017 Barth Syndrome Foundation (BSF) Research Grant Cycle, 16 annual award cycles have committed a total of US \$4.5 million to this important effort through 104 research grants to 60 principal investigators around the world. As with all BSF grant cycles, the projects from the 2017 cycle that were accepted by BSF were actually awarded the following year, thus being included in 2018 fiscal year expenses. BSF, with the advice of its international Scientific and Medical Advisory Board, and with support from international affiliates, awarded four research projects. BSF is very happy to be able to support the following grant recipients:



Borko Amulic, PhD, Lecturer (Assistant Professor), University of Bristol, Bristol, UK

"Neutrophil dysfunction in Barth syndrome"

Award: US \$49,967 over 2-year period

**Partial funding for this award was provided by Barth Syndrome Trust*



Martin van der Laan, PhD, Professor, Saarland University, Homburg, Germany

"Mutual connections of mitochondrial membrane architecture and cardiolipin homeostasis in Barth syndrome"

Award: US \$48,906 over 1.5 year period

**Funding for this award was provided by Association Syndrome de Barth France*

(Cont'd on page 8)

Science & Medicine

Research Grant Program

(Cont'd from page 7)



Miriam Greenberg, PhD, Professor, Wayne State University, Detroit, MI

“Cardiolipin activates pyruvate dehydrogenase (PDH) — a potential new target for treatment of Barth syndrome”

Award: US \$50,000 over 1-year period



Richard Epand, PhD, Professor, McMaster University, Hamilton, Ontario, Canada

“The cause and consequences of plasmalogen depletion in Barth syndrome”

Award: US \$50,000 over 1-year period

**Partial funding for this award was provided by Barth Syndrome Foundation of Canada*



Colin Phoon, MPhil, MD, Associate Professor, New York University School of Medicine, New York, NY

“Prenatal cardiac phenotype as a platform for testing Barth syndrome therapies”

Award: US \$70,000 over 2-year period

**Partial funding for this award was provided by the Paula and Woody Varner Fund*

A complete list of all grant awardees can be found on BSF's website at www.barthsyndrome.org.

(Photos courtesy of grant recipients 2017)

“I have worked with the Barth Syndrome Foundation for more than 15 years as a physician and a researcher. They are well organized and focused on education and advancing treatment for Barth syndrome for families, scientists, physicians and health professionals. They have a terrific record of funding research, including clinical, basic science and translational research. They have a unique conference every two years that brings together families, scientists and clinicians. The foundation continues to grow and is a model foundation for rare disease advocacy.” ~ Carolyn Taylor, MD, The Children's Heart Program of South Carolina, Medical University of South Carolina

Finances

Barth Syndrome Foundation (BSF) remains a financially healthy organization, ending FY 2017 with net assets of over \$3 million. This fund balance places our organization in the critical position of being prepared to fund significant potential treatment advances. Some of these — such as gene therapy — are in our near future and are likely to be a material draw on our assets.

BSF's 2017 revenues exceeded expenses by just over \$100,000. While favorable, this result was not without issues. Donations were below budget by approximately \$160,000. While fund earnings were over budget — and more than made up for the drop in donations — BSF understands the risk inherent in financial market movements.

The major expense areas for BSF in 2017 were in keeping with our mission: "Saving lives through education, advances in treatment, and finding a cure for Barth syndrome." As shown in the charts on page 10, 79% of BSF's revenues in 2017 were spent on key program areas: Family Services, Communications & Awareness, Science & Medicine and Barth Registry, and Research Grants.

We wish to thank our donors for their generosity in helping us reach our vision: A world in which Barth syndrome no longer causes suffering or loss of life.



Quentin (age 6)
(Photo courtesy of Maurita 2017)

Statement of Financial Position

For year ended December 31, 2017 (with comparative totals for year ended December 31, 2016)

Assets

	12/31/2017	12/31/2016
Assets:		
Cash & Cash Equivalents	\$ 204,805	\$ 552,960
Investments	3,752,322	3,220,066
Accounts Receivable	2,381	7,899
Prepaid Expenses	11,947	13,011
Total Assets	\$ 3,971,455	\$ 3,793,936

Liabilities and Net Assets

Liabilities:

Accounts Payable & Accrued Expenses	\$ 70,611	\$ 20,904
Deferred Revenue	8,750	0
Grants Payable	179,423	195,475
Total Liabilities	\$ 258,784	\$ 216,379

Net Assets:

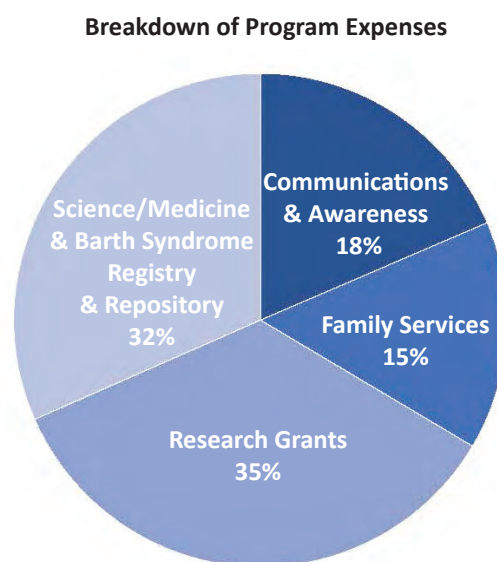
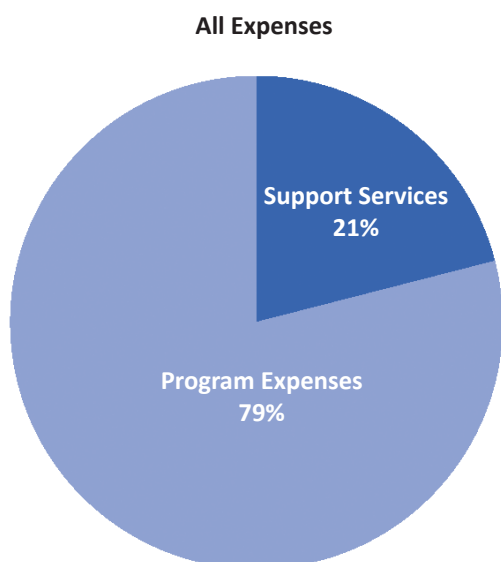
Unrestricted	\$ 1,254,271	\$ 918,886
Temporarily Restricted	2,458,400	2,658,671
Total Net Assets	\$ 3,712,671	\$ 3,577,557
Total Liabilities & Net Assets	\$ 3,971,455	\$ 3,793,936

*See annual audit for notes and additional information

Statement of Activities

For year ended December 31, 2017 (with comparative totals for year ended December 31, 2016)

	Year Ended 12/31/2017	Year Ended 12/31/2016
PUBLIC SUPPORT AND OTHER REVENUES:		
Public Support:		
Contributions	\$ 865,365	\$ 939,006
Conference Revenue	0	62,610
Grant Income	0	25,000
	\$ 865,365	\$ 1,026,616
Investment Income	200,581	92,101
Total Public Support & Other Revenues	\$ 1,065,946	\$ 1,118,717
EXPENSES AND LOSSES:		
Program Services:		
Communications & Awareness	\$ 136,354	\$ 140,368
BSF Conference	0	164,146
Family Services	110,244	107,663
Barth Syndrome Registry & Repository	16,374	20,342
Research Grants	256,449	410,648
Science & Medicine	215,892	197,295
	\$ 735,313	\$ 1,040,462
Supporting Services:		
Management & General	\$ 146,747	\$ 93,684
Development & Fundraising	48,772	80,093
	\$ 195,519	\$ 173,777
Total Expense & Losses	\$ 930,832	\$ 1,214,239
CHANGE IN NET ASSETS	\$ 135,114	(95,522)
NET ASSETS, beginning of year	\$ 3,577,557	\$ 3,673,079
NET ASSETS, end of year	\$ 3,712,671	\$ 3,577,557



Note: BSF's full 2017 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 these individuals and groups for their hard work and dedication.

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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 those affected by Barth syndrome.

Bryn (age 6)



(Photo courtesy of Kathryn 2017)

“As a scientist that interacts with affected families, I just want to state that BSF not only supports families with information, moral support, meetings, but very importantly has supported (and continues to support) research into the causes of Barth syndrome and potential therapies; this is now coming to fruition in the form of two clinical trials — all in just 17 years since BSF was created.” ~ Iris L. Gonzalez, PhD

**With your help, we are entering
a new threshold of hope — clinical trials!**



BSF Awarded Spot on 2017 Top-Rated List of Nonprofits from GreatNonprofits!



Branislav, Sr. and Team Barth members raise awareness and funds for BSF (Photo courtesy of Michal Plesnik 2017)

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