Jack, age 2

Wyatt, age 5

Noah, age 11

R.J., age 15

Andrew, age 24

Inspiration and Determination

Barth Syndrome Foundation
2012 Annual Report

Barth Syndrome Foundation®

www.barthsyndrome.org

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

Mel and Aiden, age 1

John, age 31, and Sue

Greg and Ben, age 9

TABLE OF CONTENTS

Executive Director & Chairman's Message 3

Education & Support
- Awareness 4
- Family Services 5
- Conference 6

Science & Medicine
- Barth Syndrome Registry & Repository 7
- Research 8

Finances 9

Leadership 10

Donors 12-13

Time & Advice 14

Mission, Goals, Values 15

Call to Action 16

> "The science presented at the Barth Syndrome Foundation 2012 Conference was incredible. I consider this among the most important work I have done in my career."
>
> *Colin Phoon, MD, MPhil, New York University School of Medicine and Langone Medical Center, New York, New York*

Photos on pages 1 and 2 courtesy of Amanda Clark ~ 2012

Dear Friends,

The scientific and medical advances that we helped facilitate in 2012 continue to make us optimistic about reaching our long-term goal of finding a cure for Barth syndrome. We are also proud of our successes in increasing awareness, as well as finding and caring for families affected by this life-challenging disorder. While we do not know where the next major breakthrough will come, we are giving ourselves the best chance with the best people to be "lucky" by pursuing a broad range of options. We have worked diligently to keep our global community of affected families, clinicians, scientists, donors, volunteers, and staff focused on the mission. Furthermore, we extend our reach beyond our community, as we engage in broader initiatives. The following are some of the bright spots from 2012:

- Increased awareness within the medical community and the general public
- Empowered newly identified families to become informed advocates; continued care for existing families
- Hosted our sixth highly-successful International Barth Syndrome International Scientific, Medical & Family Conference
- Funded nine research grants for a total of $341,002
- Selected as a National Institutes of Health (NIH) pilot participant in the Global Rare Diseases Patient Registry and Data Repository (GRDR) for the next phase of our Barth Syndrome Registry and Repository; expanding the accessibility and breadth of the information captured, while reducing the cost to BSF
- Raised over $870,000, maintaining our strong financial position
- Expanded use of the "Barth mouse" as a mammalian model of this human disease to more than 10 laboratories around the world
- Facilitated development of two lines of human-induced pluripotent stem cells from donors with Barth syndrome and supported initial work done with these cells
- Initiated development of a clinical trial with the drug bezafibrate in collaboration with the Science Moving Towards Research Translation and Therapy group (SMARTT) at the National Heart, Lung and Blood Institute of the NIH
- Added four new members to BSF's international Scientific and Medical Advisory Board

BSF continues to blend the best characteristics of a family-centered and a professionally managed organization. We have so much to celebrate; you deserve our greatest respect and deepest appreciation.

Thank you!

Lindsay B. Groff

Lindsay B. Groff
Executive Director

Stephen B. McCurdy

Stephen B. McCurdy
Chairman

December 2012: Barth syndrome by the numbers

Known individuals living with Barth syndrome (BTHS)	**162** in **21** countries
Increase in number of individuals identified since December 2011	**9.3%**
Grants funded since BSF was established	**72** grant awards totaling **$2.7 Million**
Individuals registered in Barth Syndrome Registry & Repository (BRR)	**78**
International Scientific, Medical & Family Conferences held	**6**
Percentage of 2012 peer-reviewed journal articles relevant to BTHS that specifically acknowledge support from BSF and/or affiliates	**50%**

EDUCATION & SUPPORT

Awareness

Fewer than 200 living individuals with Barth syndrome are known to us, but anyone who loves someone with this disorder will tell you that it touches the lives of thousands when you consider parents, siblings, grandparents, aunts, uncles, cousins, friends, and neighbors.

The magnetism of these boys and young men is undeniable. Numerous articles have featured the heroic stories of their journeys. Christopher and Henry exemplify how many boys and young men affected with Barth syndrome captivate those who know them, becoming ambassadors for even broader causes. Articles and appearances like the two below help to raise awareness about this rare genetic disorder.

Christopher kept busy in 2012, serving as the Children's Miracle Network Hospitals® Mississippi Champion. He served as an ambassador for Batson Children's Hospital and all sick and injured children in the state of Mississippi. His story of beating the odds after being given only six months to live has increased awareness of Barth syndrome from his home state all the way to the White House! (*Photo courtesy of Batson Children's Hospital, Jackson, MS.)*

Henry's story melted hearts in the Riley Messenger which came out a few days before National Doctors' Day. As a result of the article and National Doctors' Day, Henry and Dr. Grzegorz Nalepa shared their story and created awareness for Barth syndrome during radio and television interviews. *(Photo courtesy of Riley Children's Foundation and photographer, David Jaynes.)*

Family Services

"The Foundation and the Conference gave us the hope we needed — that Bryn would not have to follow in his brother's footsteps — that he could grow up." ~ *Kate, Mom*

Bryn

Bryn, age 9 months

- Family lost first son in February 2011
- Bryn born in December 2011
- Diagnosed with Barth syndrome in April 2012
- Family joined BSF in April 2012
- Attended first BSF Conference in June 2012

Kate, Bryn, age 16 months, and Sandt

(Photos courtesy of Michener Family)

The first indication of trouble with the pregnancy showed on the last scheduled fetal echo. All of the measurements were normal but the heart "looked thick." A repeat echo ended with the same frustrating result, so an echo was suggested during the first week of life. Bryn was born on December 15, 2011, and, although he was tiny, he was deemed "gestationally appropriate" and large enough not to be put on any watch lists. He also scored a 9-9 Apgar! He latched well and was a sweet, quiet, ever-watchful baby. We were hopeful that the echo would prove he was healthy—for how can a child with a cardiac problem score a 9-9?! However, the echo showed a decline in his heart function from "normal" in the fetal echo to 33% ejection fraction at day two. He also suddenly started showing signs of lethargy, and tests revealed thickened blood and a possible kidney infection. He was transferred to the Intensive Care Nursery at Children's Hospital at Dartmouth in Lebanon, New Hampshire where he spent the next 11 days.

Our world was rocked again. Bryn's heart issue appeared different than Rhys', but how could both our boys have different cardiac problems? Because Barth syndrome (BTHS) was still a suspect for Rhys' passing, Bryn was referred to Dr. Gerald Cox at Boston Children's Hospital immediately. A cardiomyopathy genetic panel was drawn, and the waiting game began again. Biochemical urine tests were done, and roughly one year after Rhys' passing, we got the call from our genetic counselor: lab results from Amsterdam indicated BTHS for Rhys, the urine tests for Bryn indicated the same. They were 99.9% sure—the *tafazzin* (*TAZ*) mutation was really just a formality. We got the final genetic results for both boys in early April.

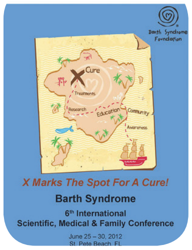
We struggled with the issue that, while Bryn looked so good, he had a disease that had claimed his brother. Friends and family alike could not fully comprehend our anxiety and would, understandably, get frustrated with our reclusiveness. Then, we discovered an entire community of people who not only got the "chronic illness" thing, but understood BTHS as well. Our experience at BSF's 2012 Conference was nothing short of amazing. Interacting with other affected families showed us that these boys could thrive. Meeting the people who are treating and researching BTHS helped us to understand what Bryn was going through. The Foundation and the Conference gave us the hope we needed—that Bryn would not have to follow in his brother's footsteps—that he could grow up.

2012 Family Services Spotlight

- Provided support for 162 affected individuals and their families throughout 2012
- Increased the number of affected individuals and families who BSF and/or BSF affiliates serve by 9.3%
- Monitored the family listserv with a total of 3,092 posts
- Conference provided education and support to 187 family members, 44 of whom were affected males

Conference

> **"Interacting with the Barth syndrome boys and their families, both in conversation and in dance, was indescribably rewarding. Hearing first-hand about life with Barth syndrome made it abundantly clear that what I do matters and may ultimately make a difference."** ~ *Steven M. Claypool, PhD, Department of Physiology, Johns Hopkins School of Medicine, Baltimore, MD*
>
> *(Photo courtesy of Dr. Steven Claypool)*



The 2012 Conference was hailed as an outstanding success by all attendees, including those affected by Barth syndrome, family members, clinicians, and researchers. The Conference included 44 individuals with Barth syndrome, their families, and nearly 50 physicians and researchers in several tracks of simultaneous meetings to hear about the progress made in this field. In all, over 330 people attended this incredible event—a new record.

Researchers & Physicians

- Engaged in cutting-edge scientific presentations and discussion
- Collaborated with other experts in multiple fields to further understand the clinical aspects of this disorder

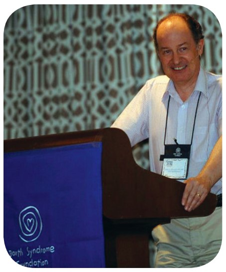
Affected Individuals & Families

- Learned about medical management from clinicians and families experienced with Barth syndrome
- Heard updates from the scientists on the front lines of clinical and basic research

All Attendees

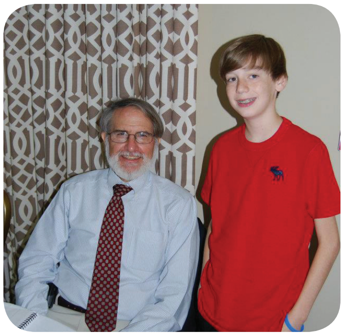
- Strengthened connections and shared information that benefits the entire community
- Made lifelong friendships; increased commitment to the mission

Dr. Steward Presented with Varner Award for Pioneers in Science and Medicine



BSF's 2012 Varner Award for Pioneers in Science and Medicine was awarded to Colin G. Steward, PhD, FRCP, FRCPCH, for his contributions to the science and medicine of Barth syndrome (BTHS). This biennial award is given to a scientist or physician whose dedication to work in his or her field has made a positive and lasting impact on Barth syndrome.

Dr. Steward stands firm in his conviction that Barth syndrome is under-diagnosed, leading him to work tirelessly to raise global awareness about the disorder. In addition, his tenacious leadership has helped expand and improve services for Barth syndrome families in the UK, and he heads the trail-blazing NHS-supported Barth syndrome clinic at the Bristol Royal Hospital for Children that he was instrumental in creating. His dedication and genuine compassion continue to improve the lives of many affected individuals and their families around the world, so it is no surprise that people have described Dr. Steward as determined, honest, approachable, and respectful. His efforts have made a significant and lasting impact within the Barth syndrome community and beyond.




SCIENCE & MEDICINE

"I am so happy for your progress and look forward to seeing your registry up and running. I am sure that your registry will be one of the models for success. Interacting with organizations like BSF makes our work much more pleasant and gives us a sense of the collaborative effort to fulfill our goals." ~ *Yaffa Rubinstein, PhD, Director of Patient Resources for Clinical and Translational Research, Office of Rare Diseases Research, National Center for Advancing Translational Sciences, National Institutes of Health*

(Photo courtesy of Dr. Yaffa Rubinstein)

BSF Accepted into NIH-Sponsored Pilot Program

Barth Syndrome Registry and Repository®

The Barth Syndrome Foundation (BSF) was selected to participate in a two-year pilot project of the National Institutes of Health (NIH) called the Global Rare Disease Registry and Data Repository (GRDR). As a pilot participant, BSF will work in collaboration with leaders in rare disease research at the Office of Rare Diseases Research, National Center for Advancing Translational Sciences, National Institutes of Health, PatientCrossroads, Children's Hospital of Philadelphia, and WebMD. The GRDR program will collect de-identified patient health information from participating registries established by the individual rare disease organizations in order to allow analyses of data across many rare diseases as well as to facilitate clinical trials and other studies.

This GRDR program builds on our existing registry. To add to the excitement, a new publication entitled, **The Barth Syndrome Registry: Distinguishing disease characteristics and growth data from a longitudinal study.** (Am J Med Genet A. 2012 Oct 8. doi: 10.1002/ajmg.a.35609 [Epub 2012 Oct 8]) has been released. This paper is an important addition to the field of Barth syndrome clinical knowledge. As the title states, the data collected by the Barth Syndrome Registry & Repository (BRR) are presented for all to reference. Publications like this allow researchers to use the information collected in the BRR to advance our understanding and to help find specific treatments for Barth syndrome. The BSF community has benefited from the research that has emerged in the last decade, and we expect the GRDR effort to attract even more efforts to test scientific or clinical theories.

Expansion of Scientific and Medical Advisory Board

The Barth Syndrome Foundation's (BSF) international Scientific and Medical Advisory Board 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 members, each of whom has agreed to serve for a four-year term. These additions include more sub-specialties, perspectives, and experiences to broaden our horizons and the breadth of our collaborative team.

- **W. Todd Cade, PT, PhD**, Assistant Professor of Physical Therapy and Internal Medicine, Washington University School of Medicine, St. Louis, MO, USA
- **William T. Pu, MD**, Associate Professor, Harvard Medical School; Department of Cardiology, Boston Children's Hospital; Principal Faculty, Harvard Stem Cell Institute, Boston, MA, USA
- **Mindong Ren, PhD**, Associate Professor, Department of Cell Biology, New York University School of Medicine, New York, NY, USA
- **Arnold W. Strauss, MD**, BK Rachford Professor and Chair, Department of Pediatrics, University of Cincinnati College of Medicine; Director, Cincinnati Children's Research Foundation; Chief Medical Officer, Cincinnati Children's Hospital Medical Center; Professor, UC Department of Pediatrics, Cincinnati Children's Hospital, Cincinnati, OH, USA

Barth Syndrome Researcher Obtains NIH Award

W. Todd Cade, PT, PhD, Assistant Professor of Physical Therapy and Internal Medicine, Washington University School of Medicine, St. Louis, MO, has received an award from the National Heart, Lung and Blood Institute of the National Institutes of Health for his R01 grant entitled, **"Heart and Skeletal Muscle Metabolism, Energetics and Function in Barth Syndrome."** This award is distributed over five years and is in the amount of $1.6 M. This is a significant achievement for which BSF is very proud and excited. Dr. Cade began recruitment for patient participation for this research project at BSF's 2012 Conference!

BSF Accepted into SMARTT Program

BSF has been accepted into the Science Moving towards Research Translation and Therapy (SMARTT) Program, a part of the National Heart, Lung and Blood Institute of the National Institutes of Health, which supports the translation of novel discoveries into successful new therapies for heart, lung, and blood diseases by providing free, confidential, and rapid preclinical development services to investigators. BSF is working with SMARTT to develop a clinical trial using the drug bezafibrate.

Research Grant Program

With the completion of the 2012 Barth Syndrome Foundation (BSF) Research Grant Cycle, 11 annual award cycles have committed a total of over $2.7 million to this important effort through 72 research grants to 43 principal investigators. As with all BSF grant cycles, the 2012 cycle grants were awarded the following year, thus being included in 2013 fiscal year expenses. BSF, with the advice of its international Scientific Medical & Advisory Board, and with support from international affiliates, awarded nine research projects. This competitive grant program has resulted in many publications which further describe scientific and medical components of this multi-faceted disease and are leading towards new ideas for treatment. A complete list of all grant awardees can be found on BSF's website at www.barthsyndrome.org, and those awarded in the 2012 cycle are:

William T. Pu, MD, PhD, Associate Professor, Boston Children's Hospital, Boston, MA, USA

Maturation of Barth syndrome models for clinical translation

Award — $40,000 over 1-year period*

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

Relationship between membrane physical properties and the action of *tafazzin*

Award — $37,950 over 2-year period****

Colin Phoon, MD, MPhil, Associate Professor, New York University Medical Center, New York, NY, USA

Role of mitochondria during myocardial morphogenesis in Barth syndrome

Award — $40,000 over 1-year period**

Matthew P. Gillum, PhD, Research Assistant Professor, University of Iowa, Iowa City, IA, USA

Implications of phosphatidylserine deficiency in skeletal muscle and heart of ROSA26-*taz* shRNATet-on mouse model of Barth syndrome

Award — $40,000 over 1-year period

Yuguang (Roger) Shi, PhD, Professor, Pennsylvania State University School of Medicine, Hershey, PA, USA

Regulation of cardiomyopathy by ALCAT1 in Barth syndrome

Award — $40,000 over 1-year period

Robert Ryan, PhD, Senior Scientist, Children's Hospital and Research Center at Oakland, Oakland, CA, USA

Cardiolipin replacement therapy for Barth syndrome

Award — $40,000 over1-year period

Adam Chicco, PhD, Assistant Professor, Colorado State University, Fort Collins, CO, USA

Mechanisms of substrate-specific impairment of oxidative phosphorylation in *taz*-deficient cardiac mitochondria

Award — $40,000 over 1-year period

Michael T. Chin, MD, PhD, Associate Professor University of Washington, Seattle, WA, USA

***Tafazzin* enzyme replacement therapy for heart muscle in Barth syndrome**

Award — $40,000 over 1-year period

Angela Corcelli, PhD, Associate Professor University of Bari, Aldo Moro, Bari, Italy

Determination of the monolysocardiolipin/cardiolipin (MLCL/CL) ratio in intact nucleated cells: A new tool for the screening of Barth syndrome

Award — $36,300 over 1-year period***

**Funding for this award was provided by Barth Syndrome Trust (UK & Europe)*
***Funding for this award was provided by the Paula & Woody Varner Fund*
****Funding for this award was provided by Association Barth France*
*****Funding for this award was provided by BSF and BSF of Canada*

(Photos courtesy of individual researchers)

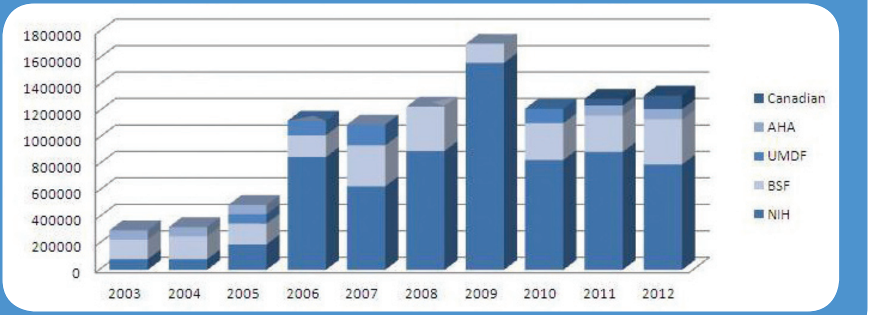
Barth Syndrome Research Funding Sources

(by fiscal year)

BSF's smaller research grants are meant to attract talented researchers whose initial work then successfully receives greater funding from larger institutions.

Our strategy continues to produce great results!

BSF Seed Grants Attract Institutional Research Funding



FINANCES

Charity watchdogs have always used financial statements as simplistic measures of charities' worthiness and expressions of responsible management. By all measures, the Barth Syndrome Foundation's (BSF) recent audited financial statements once again show very strong performance. 2012 produced a slight deficit of $75,864 despite investing $341,002 in nine research grants (the 2011 cycle awarded in early 2012) and bearing the costs of our biennial conference. BSF also continues to maintain a sizeable reserve of $1.8 million in net assets which enables us to take measured risks and confidently invest in our future. We continued to spend less than five cents per dollar raised in fundraising expenses, and more than 81% of total expenses on our programs—better than most charities. We again earned the highest ratings from the Better Business Bureau and met all 43 measures of good governance required by the National Health Council.

More importantly, we remain intensely focused on our mission to make sure that our programs (described in earlier pages of this report) are the best that they can be. The BSF Board and staff are constantly learning from other groups' best practices, finding new and inventive ways to accomplish our goals with limited resources. Our greatest thanks go to our donors whose continued financial support enables everything. You are truly our "angels!"

Suzy, Mitchell, age 7, and Jerry

Statement of Financial Position

December 31, 2012 (with comparative totals for year ended December 31, 2011)

Assets

	12/31/2012	12/31/2011
Assets:		
Cash & cash equivalents	$ 565,387	$ 329,443
Investments	1,303,620	1,499,571
Accounts receivable	37,186	163,351
Prepaid expenses	3,592	2,148
Total assets	**$ 1,909,785**	**$ 1,994,513**

Liabilities and Net Assets

	12/31/2012	12/31/2011
Liabilities:		
Accounts payable & accrued expenses	$ 29,938	$ 19,302
Grants payable	60,500	80,000
Total liabilities	**90,438**	**99,302**
NET ASSETS:		
Unrestricted	849,083	937,779
Temporarily restricted	970,264	957,432
Total net assets	**1,819,347**	**1,895,211**
Total liabilities & net assets	**$ 1,909,785**	**$ 1,994,513**

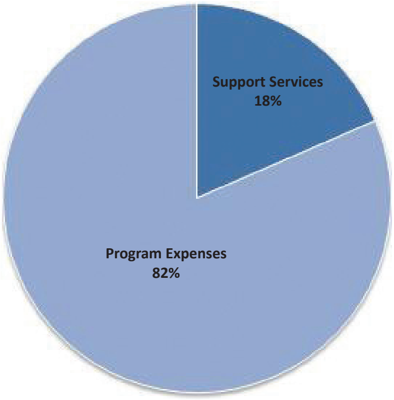
*See annual audit for notes and additional information

Statement of Activities

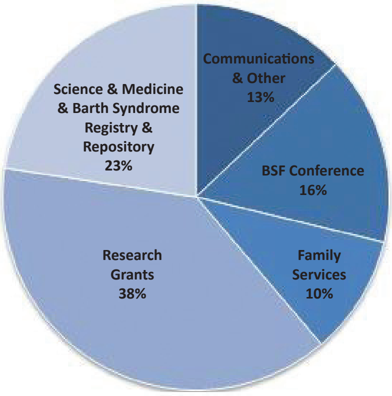
For the Year Ended December 31, 2012 (with comparative totals for the year ended December 31, 2011)

	Year Ended 12/31/12	Year Ended 12/31/11
PUBLIC SUPPORT AND OTHER REVENUES:		
Public Support:		
Contributions	$ 871,480	$ 706,090
	871,480	706,090
Investment Income	7,975	11,094
Unrealized Gain (Loss) on Investments	990	(1,766)
Total Public Support & Other Revenues	**880,445**	**715,418**
EXPENSES AND LOSSES:		
Program Services:		
Communications & Other	100,710	67,997
BSF Conference	123,515	7,833
Family Services	78,148	69,098
Barth Syndrome Registry & Repository	4,800	88,901
Research Grants	340,823	262,115
Research Grants Funded Directly by BSF of CA	(40,000)	(38,350)
Science & Medicine	171,408	164,629
	779,404	**622,223**
Supporting Services:		
Management & General	137,384	119,616
Development & Fundraising	39,521	10,827
	176,905	130,443
Total Expense & Losses	**956,309**	**752,666**
CHANGE IN NET ASSETS	(75,864)	(37,248)
NET ASSETS, beginning of year	1,895,211	1,932,459
NET ASSETS, end of year	**$ 1,819,347**	**$ 1,895,211**

All Expenses



Breakdown of Program Expenses



Note: BSF's full 2012 audited financials are available on our website at www.barthsyndrome.org.

LEADING THE WAY

The Barth Syndrome Foundation's 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 community that provide the bulk of the funding for our programs. BSF wishes to thank and recognize all of the individuals for their hard work and dedication.

Barth Syndrome Foundation
PO Box 618
Larchmont, NY 10538

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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

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W. Todd Cade, PT, PhD; Physical Therapy & Internal Medicine, Washington University School of Medicine, St. Louis, MO, USA	**Colin G. Steward, PhD, FRCP, FRCPCH**; Pediatric Hematology, Royal Hospital for Children, Bristol, England
Gerald F. Cox, MD, PhD; Clinical Genetics, Children's Hospital Boston, Boston, MA; Clinical Research, Genzyme Corporation, Cambridge, MA, USA	**Arnold Strauss, MD**; Pediatrics and Research, Cincinnati Children's Hospital Medical Center; Cincinnati Children's Research Foundation, Cincinnati, OH, USA
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Grant M. Hatch, PhD; Lipid Lipoprotein Research, University of Manitoba, Winnipeg, Canada	**Katherine R. McCurdy** – *ex-officio*; Board of Directors, BSF
Richard I. Kelley, MD, PhD; Metabolism, Kennedy Krieger Institute, Johns Hopkins University, Baltimore, MD, USA	**Matthew J. Toth**, PhD – *ex-officio*; Science Director, BSF

2012 DONORS

PAULA & WOODY VARNER FUND

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

Dillon Foundation

General Contributions ($50 - $999)

Bettenhausen, Bob & Joanne
Buckley, Les & Nancy
Burmeister, Jon & Jackie
Burmeister, Charles & Marita
Campbell, Jack & Sally
Campbell, Robert & Candace
Cimino, Dr. Mike & Patty
Gelber, Dr. Ben & Elaine
Haessler, John & Nancy
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McNair, G. L.
Pittenger, Jim & Julie
Raun, Robert & Eileen
Roskens, Ronald & Lois
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Seaman, Andrew & Robyn Steely
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Stuckey, Dennis & Nancy
Varner, Judy
Wilkins, Dr. Jerry
Wilkins, Joanne
Wilkins, Muriel
Wilkins, Sue & Dr. Mike

SCIENCE & MEDICINE FUND

Stars ($5,000+)

Allen, Tiffini
Association Barth France
Barth Syndrome Foundation of Canada
Barth Syndrome Trust
McCurdy, Steve & Kate
Sernel, Marc & Tracy

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

Clark, Robert (Seeds of Hope)
Kugelmann, Peter & Karen
Kugelmann, Steve & Jan
Olson, Richard & Sharon
Winston, Laura

General Contributions ($50 - $999)

Allen, John & Karen
Baron, John & Christine
Barrett, James & Nancy
Caille, Jan & Karen
Campbell, Tonja
Citta, Laura
Clark, Jeffrey
Clark, Bob & Randy Galbreth
Davis, Samuel & Susan
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Keller, Allan & Floriene
Lloyd-Jones, Kimball & Mary
MacDonald, Grant
Mansfield, Anne
Nishi, Michael
Nurkowski, John
Roberts, John & Betty
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Robinson, Joe & Connie Sue
Ryan, James & Miriam
Stahly, Craig (Priority One Construction)
Watson, Theda
Wayne, Alexander
Wiley, Troy & Gracie
Wilkins, Sue & Dr. Mike
Yancy, Dr. Eric

GENERAL FUND

Stars ($5,000+)

Cusack, Tom & Carrie
The Frill Foundation
Grubb & Ellis
The Lebensfeld Foundation
Lummis, Marilyn
Lummis, William & Dossy
Malkin, Scott & Laura
Malkin, The Malkin Fund
McKown, Christopher & Abigail Johnson
Pierson, Dr. Richard & Allene
Russell, Allene & Paul Russell Fund
Sernel, Gordon & Sharon
Shapiro, Brenda

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

American Express PAC Match
Anonymous
Association Barth France
Barth Syndrome Foundation of Canada
Bailey, Clarke & Patricia
Baker, Timothy
Barad, Seth & Amy
Bowen, Shelley
Buly, Dr. Robert & Lynne
Condon, Owen
Davis, Martha (Schwab Charitable Fund)
Dell Giving
Despins, Suzanne
Dooley, Adam
Epstein, Paul & Leah
Evoy, Larry & Sally
Galbraith, Lois
Geary, Ann
Glenn, William
Greenberg, Dr. Miriam & Shifra
Hales, Bryan
Hall, Greg & Dacey
Hart, Dana
Hechinger Family Charitable Gift Fund
Henricks, Dr. Bruce & Peggy
Hixson, Christina
Ingersoll, Ann
Isaac, Paul & Karen
Jewish Communal Fund
Johnson, Malcolm & Deloris
Joyce, David & Jane
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Levi, age 1

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.

Connor, age 2

Our Goals

- Advocate for timely and accurate diagnosis
- Increase impact of Barth Syndrome Registry & Repository
- Encourage, guide, and fund research
- Help develop effective treatments
- Grow and strengthen our caring and informed community
- Expand base of committed contributors

Devin, age 8

Our Values

- Credibility, integrity, professionalism, and compassion
- Inspire, support, and be good stewards of volunteers and staff
- Place the interests of all those affected by Barth syndrome above the interest of any individual
- We will never give up!

To learn more or to donate, go to www.barthsyndrome.org.

With your help, we are moving forward together!

All photos courtesy of BSF unless otherwise noted.

Raphaël, age 4

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