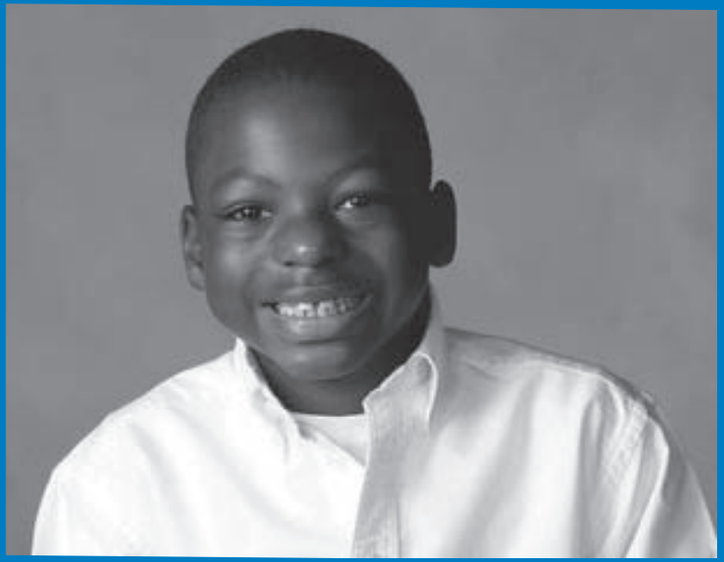
Barth Syndrome Foundation



Photos courtesy of BSF

Barth Syndrome Foundation®

www.barthsyndrome.org

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

2011 Annual Report

Photo courtesy of Barth Syndrome Trust ~ 2011

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Historically, boys died of heart failure or infection by three years of age, but with improved diagnosis, appropriate medical treatment, and monitoring of all symptoms, the survival rate and future of these individuals is much brighter.

CHAIRMAN'S MESSAGE

Dear Friends,

I am pleased to report that, by all measures, the Barth Syndrome Foundation (BSF) remains quite healthy. This is good news for all those who suffer from this rare, disruptive and sometimes deadly disorder, and for all those who care about them.

We saw positive signs of health and growth in virtually every key area of importance to BSF, some of which are noted below and described more fully elsewhere in this annual report:

- Financially, BSF finished the year with a modest deficit and net assets of more than $1.8 Million.
- Increased the number of affected individuals and families served by BSF by 14%.
- Welcomed a new, fourth international affiliate, Association Barth France.
- Awarded seven new research grants worth $273,770, and one of our veteran researchers won a major grant from the National Institutes of Health.
- Seven international laboratories are actively working with our *tafazzin* knockdown mouse (a mouse model of Barth syndrome) which is now available globally through Jackson Laboratories.
- Hosted three family outreach gatherings, bringing together families from across North America to learn more about Barth syndrome and to gain the support of other families who are on a similar path.

In addition, there is another equally important sign of a healthy organization that ensures that it can continue to make great progress in the years ahead, and that is its ability to evolve and renew itself. 2011 marked a year of transition for BSF.

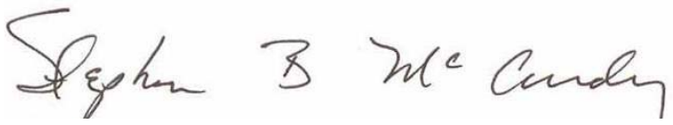
BSF worked without an Executive Director for more than a year until we hired Lindsay Groff. Lindsay is an experienced, energetic and dedicated woman whose leadership and management skills are already evident, as is her respect for the history and accomplishments of BSF and her immediate adoption of the Barth family as her own. Equally impressive were the Board and staff's willingness to step up to fill the void until Lindsay stepped in. A sign of a healthy organization!

After ten years, Dr. Richard Kelley stepped down as Chairman of our international Scientific and Medical Advisory Board (SMAB) (but remained an active member of the SMAB). Dr. Michael Schlame, another dedicated researcher, leader and scientific evangelist for Barth syndrome, willingly stepped up to the chairman's role. Another sign of a healthy organization!

Some years ago, the BSF Board instituted term limits for its members, as well as a rigorous process to search for new board members to sustain the rate of progress and ensure a dedicated, diverse, and resourceful board. In 2011, we added Susan McCormack, Dr. David Axelrod, and John Wilkins to the BSF Board, each of whom brings a unique and valuable new perspective to the deliberations and decision making of the board. Yet another sign of organizational health!

As we evolve as an organization, it is also important to develop as individuals. Shelley Bowen exemplifies the kind of selfless focus on our vision that will help in this evolution. Shelley has suffered great loss in her family as a result of Barth syndrome, and yet she personifies our mantra that "we will never give up!" As a founder and former President of BSF, she has poured her heart and soul into this organization employing, "what's best for the boys and young men" as her litmus test for decision making. Her willing transition to become Director of Family Services & Awareness returns her to the core of what she does best and loves most.

BSF exits 2011 as a healthy organization, continuing to make great progress in the medical and scientific arenas, continuing to grow and care for our families, and effectively managing key organizational transitions. We look forward with confidence to accelerated growth in 2012.



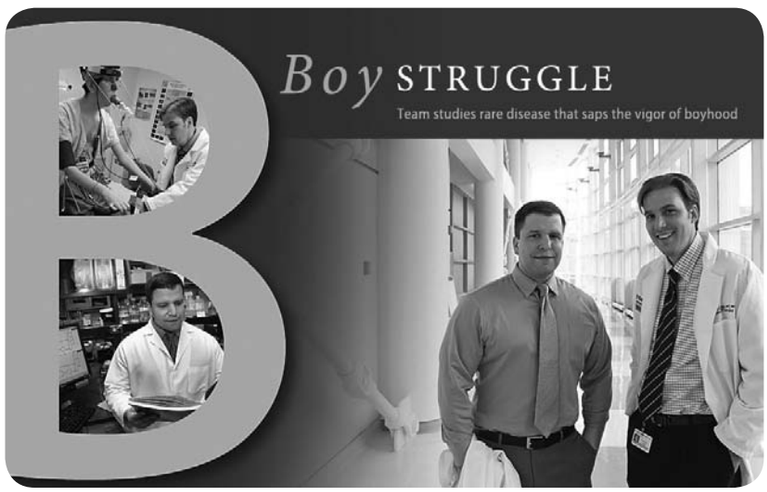
EDUCATION AND SUPPORT

Awareness

It has long been our belief that awareness is vital to the early and proper diagnosis of Barth syndrome which, in turn, leads to improved approaches to care. Ninety percent of the mortality associated with this disorder is found in the first decade of life, with most of these tragic deaths occurring in the first year. In addition, we know there are many losses during pregnancy. Education and support about Barth syndrome remains an integral priority to save those who have Barth syndrome. Our first priority lies in advocating for an accurate diagnosis. Barth syndrome is never too rare to consider as a diagnosis. **Through our awareness efforts we are finding and helping affected families around the world.**

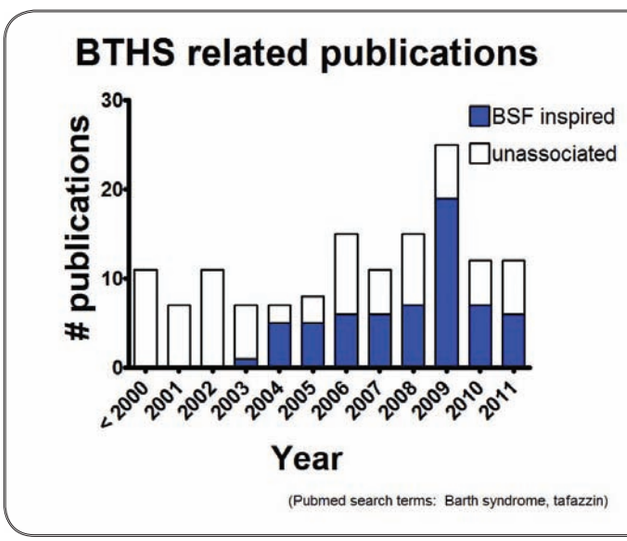
"We want these kids to get better and lead long, healthy lives."

W. Todd Cade, PT, PhD



Permission given from Washington University School of Medicine, St. Louis, MO, USA.

Washington University School of Medicine, St. Louis, prominently featured two researchers devoted to finding a cause and effective treatments for Barth syndrome. W. Todd Cade, PT, PhD and Michael A. Kiebish, PhD splashed the front page of the August 2011 edition of Outlook, a digital magazine produced by the university. Their dedication is evident. "We put Barth syndrome up front because it's worth it," says Kiebish. "Every inch forward makes miles of difference." Publications, like this article, help to increase awareness about Barth syndrome around the world. BSF is honored to have awarded research grants to both Dr. Cade (2008; 2009; 2011) and Dr. Kiebish (2009).



As of December 2011, there was a total of 60 distinct publications acknowledging financial support and/or biological samples (and/or information) from Barth families, the Barth Syndrome Registry and Repository (BRR), and BSF and/or its affiliates. A complete library of publications is available on BSF's website, along with links to all publications included in our bibliography. This can be found at: *Home » Bibliography*

Through BSF's awareness efforts, more children are now being screened and diagnosed for Barth syndrome in the first year of life, and an increasing number are being diagnosed *in utero*.

Family Services

"The Barth Syndrome Foundation is our lifeline. They have been there to support us daily through good times, bad times, and even the very darkest days." ***Brie Chandler-Kalapasev***

Milosh was born in heart failure. Because of this, all his other organs went into failure within 24 hours. He spent the first four months of his life in a cardiac intensive care unit. He went home initially on the heart transplant list. Milosh's parents, Ned and Brie, felt lost.

The future for Milosh was unpredictable. Every step along the way seemed interminably long. Ned and Brie received much-needed support throughout those long, dark days by BSF's Family Services Program. Those daily phone conversations served as a lifeline for the Kalapasev Family.

After six 'good' months at home, Milosh's heart worsened. His doctors obtained a compassionate waiver to use a Berlin external mechanical heart (used in Europe and pending FDA approval). During surgery, other complications arose. A new procedure was tried; the Berlin Heart was kept in place and the "mechanical lung" connected. Milosh became the first baby in the world to have this life-giving device, now affectionately called BECMO, buying him more time. After an agonizing wait of 29 days, came the news of a new heart! Ned and Brie felt overwhelmed with immense gratitude, coupled with sadness, for the compassionate donor family who was facing the tragic loss of their child.

Milosh's recovery has been slow but steady. The Kalapasev family endured things no parent should ever have to experience, a true rollercoaster ride of emotions. They have learned to savor every positive test result, every reached milestone, and each heart-melting smile that lights up the room. Ned and Brie continue to share news of Milosh's progress with their extended BSF family — united by their care for each boy and young man in this struggle.

Photo courtesy of Chandler-Kalapasev Family ~ 2011

- Born in heart failure in February 2010
- Diagnosed with Barth syndrome in March 2010
- Family joined BSF in April 2010
- Received a heart transplant in April 2011

Through a united effort among clinical experts and BSF, Barth syndrome no longer disqualifies someone from being considered for a heart transplant.


Photo courtesy of Amanda Clark

Ned, Brie, Bella, and Milosh.

2011 Family Services Spotlight

- Provided support for 151 affected individuals and their families throughout 2011
- Grew the number of affected diagnosed individuals and families who BSF and/or BSF affiliates serve by 14% (18 newly diagnosed individuals and their families)
- Monitored the family listserv with a total of 3,579 posts (original posts = 615)
- Hosted three family outreaches to provide support and education to families across North America

Family Outreaches

In 2011, the Barth Syndrome Foundation, with the assistance of the Family Services Team and volunteers, hosted three family outreaches, bringing together families from across North America to learn more about Barth syndrome and to gain the support of other families who are on a similar path.

Great Plains Family Outreach ~ June 2011 in Lincoln, Nebraska

Families from Nebraska, Iowa, and Indiana, as well as Saskatchewan, Canada enjoyed precious time together at the first ever Great Plains Family Outreach. ***"It was such a joy to spend time with others who know and understand Barth syndrome after all these years of being alone."*** *John Wilkins, Affected Individual - age 30*

Southeast Family Outreach ~ June 2011 in Steinhatchee, Florida

Families drove from as far as Georgia and Texas to enjoy a day paddling on the Steinhatchee River, playing with animals in the petting zoo, and sharing a weekend of fellowship. ***"The culture of friendship and devotion to one another within this community extends beyond the disease that initially brought us together."*** *Shelley Bowen, Director of Family Services & Awareness*

Midwest Family Outreach ~ July 2011 in Indianapolis, Indiana

Excessive heat didn't stop Devin, Henry, Wyatt, Noah, John, Dylan and Peyton, and their family members from traveling a total of 1,557 miles to be together for the Midwest Barth Syndrome Outreach. ***"Friends were reunited and new friendships were created; the laughter never ended!"*** *Tiffini Allen, Mom to Henry - age 3*

Photos courtesy of BSF ~ 2011

SCIENCE AND MEDICINE

Barth Registry & Repository

Re-defining, Re-engineering, Re-tooling

The Barth Registry & Repository (BRR) is a valuable resource that saves researchers considerable time and effort. Because Barth syndrome is rare, having a registry of individuals with a confirmed diagnosis eliminates the need for individual scientists to spend time finding patients and then collecting samples and data. Instead, the investigators can immediately get started on their research using the BRR's collection of DNA and cell lines along with continually updated and detailed medical information. Researchers around the world have accessed the anonymous medical information and/or DNA for their pioneering work. In England, Dr. Colin Steward is focusing on neutropenia using hematology data. In France, Dr. Patrice Petit's research focuses on the role of cardiolipin in proper mitochondrial membrane function. Using 25 cell lines from the BRR for research, he has had two recent publications. To further improve the usefulness of the BRR, Dr. Bill Pu at Children's Hospital Boston has been working on developing stem cell lines (from fibroblasts) that will eventually be stored at Johns Hopkins Cell Center and made available to researchers.

BSF has earned a cutting-edge reputation in medical research and treatment, particularly with the Barth Registry & Repository. First, BSF paved the way by establishing one of the few rare disease patient registries in existence. **To date, this invaluable resource has collected data from 79 affected individuals and has gathered biological samples from 45. This is the world's largest deposit of medical information about Barth syndrome.**

Many advances have been made since the initial creation of the BRR, but the Foundation never rests on its laurels. Like many innovative organizations, BSF recognized that some re-engineering was required to take this project to the next level. With the help of our partners at University of Florida and Boston Children's Hospital, BSF formed a committee to examine the challenges while evaluating what changes were needed. The BRR Committee researched and reviewed the best practices of other successful organizations in a committed effort to continue to deliver on the promise of an effective registry and repository.

As a result of this expert research, the Foundation is poised to apply new, innovative approaches to this valuable program. The BRR offers the most direct way that families can contribute to scientific research and to clinical advances made on Barth syndrome. We wholeheartedly thank those experts and families who got us this far and look forward to this next chapter which we believe will take us far forward.

BSF Researcher Obtains NIH Award

Perseverance is one characteristic that often makes advances in science and medicine possible. Barth Syndrome Foundation (BSF) research grant recipients, Drs. Zaza Khuchua and Arnold Strauss of the Cincinnati Children's Hospital Medical Center show perseverance. The initial research goal for this team was to develop a genetically altered mouse with Barth syndrome. Their efforts, as well as those of several other laboratories, did not succeed. For reasons that are still unknown, making what is called a knockout mouse with the gene responsible for Barth syndrome, *tafazzin*, has never been successful. Faced with that stumbling block, the BSF community went to a new technology to produce what is known as a knockdown mouse. Drs. Khuchua and Strauss never gave up and quickly obtained these *tafazzin* knockdown mice. They were the first to publish their results which showed that the knockdown mice are a remarkably faithful mammalian model of this rare disorder. Dr. Khuchua first presented his results at BSF's 2010 International Scientific, Medical & Family Conference to a welcoming audience — an audience excited to see such a significant advancement.

Along with his professional success, Dr. Khuchua's work also clearly demonstrates the importance of the BSF Research Program and the BSF biennial conferences. **Building on the early financial support from BSF and the interactions with his colleagues in the BSF research community, Dr. Khuchua received an R01 grant from the NIH in 2011 to study the knockdown mouse in greater detail.** R01 grants are the basic large research grant awarded to investigators at the very top of their profession. These grants provide large amounts of money (typically nine times the amount of a BSF research grant) and are sustained over multiple years. This is exactly what the BSF Research Grant Program was designed to do. The Foundation is very fortunate to have researchers like Drs. Khuchua and Strauss who persevere in the face of initial disappointment, seizing another opportunity as it arises.

Research Grant Program

With the completion of the 2011 Barth Syndrome Foundation (BSF) Research Grant Cycle, ten annual award cycles have committed a total of over US $2.3 million to this important effort through 63 research grants to 38 principal investigators. As with all grant cycles, the 2011 cycle completed in January of 2012, with the awards booked in the 2012 fiscal year. BSF, with the advice of its international Scientific Medical & Advisory Board (SMAB), and with support from international affiliates, awarded nine research projects. The funding of these grants will foster a better understanding of Barth syndrome (BTHS) in both a scientific and a clinical manner by providing funding for basic science and clinical research on the natural history, biochemical basis, and treatment of Barth syndrome. A complete list of all grant awardees can be found at: *Home » Research Grant Program » Grants Awarded.*

2011 Grant Awardees

Steven M. Claypool, PhD, Johns Hopkins University, Baltimore, MD, USA

Characterizing endogenous mammalian *TAZ*1

Award — US $40,000 over 1-year period

Grant Hatch, PhD, University of Manitoba, Winnipeg, Manitoba, Canada

MLCL AT-1 elevates cardiolipin and mitochondrial function in cardiac myocytes of *taz* knockdown mice

Award — US $40,000 over 1-year period**

William T. Pu, MD, Children´s Hospital of Boston, Boston, MA, USA

Using induced pluripotent stem cells and modified RNAs to model and correct BTHS

Award — US $40,000 over 1-year period

Yana Sandlers, PhD, Kennedy Krieger Institute, Baltimore, MD, USA

Characterization of biochemical abnormalities in BTHS patients and mouse model of BTHS.

Award — US $21,065 over 1-year period

Mindong Ren, PhD, New York University School of Medicine, New York, NY, USA

Drug repositioning for BTHS

Award — US $40,000 over 1-year period

Ji Zhang, MD, PhD, University of California at San Diego, San Diego, CA, USA

Functional characterization of a mitochondrial lipid phosphatase that involves cardiolipin biosynthesis

Award — US $40,000 over 2-year period

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

Cardiolipin deficiency leads to defects in the TCA cycle

Award — US $40,000 over 1-year period*

Junhwan Kim, PhD, Case Western Research University, Cleveland, OH, USA

Causative and correlative role of cardiolipin on integrated mitochondrial function in BTHS

Award — US $40,000 over 1-year period

W. Todd Cade, PT, PhD,Washington University School of Medicine, St. Louis, MO, USA

Effects of resistance training on cardiac, metabolic, and muscle function and quality of life in BTHS

Award — US $39,937 over 1-year period

****Funding for this award was provided by Association Barth France.*

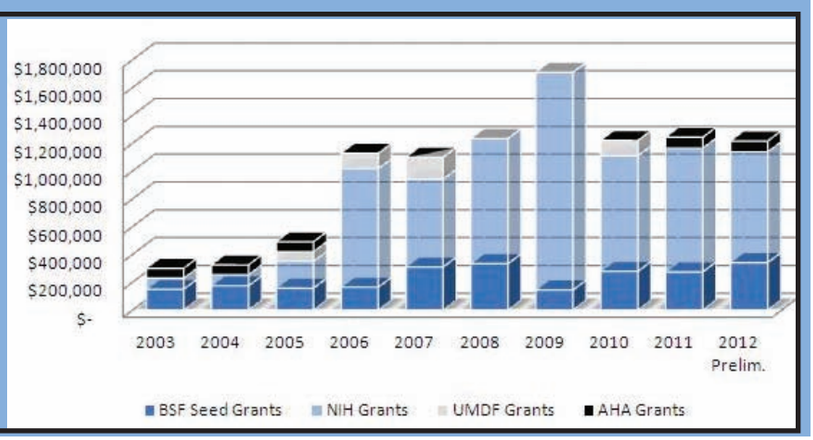
*****Funding for this award was provided by BSF of Canada.*

Photos courtesy of BSF ~ 2011

Barth Syndrome
Research Funding Sources
(by fiscal year)

BSF's smaller research grants
are meant to attract talented researchers
who then successfully seek
greater funding from larger institutions.

Our strategy continues to produce great results!



FINANCES

The Barth Syndrome Foundation (BSF) finished 2011 with a slight deficit of $37,248, a marked improvement over our 2010 deficit of $271,861. 2011 was not a conference year (the conference is held every other year) accounting for the majority of the year-to-year variance in deficits. Research grants awarded in 2011 (of $262,115) were approximately the same level as those awarded in 2010. Staffing has remained constant over the past several years except during the search for a new Executive Director. In both 2011 and 2010, BSF directed 84% of its expenditures to programs and only 16% was split between fundraising, administrative, and general expenses.

BSF's balance sheet continued to be strong with $1,895,211 in Net Assets split 49% / 51% between Unrestricted and Temporarily Restricted categories, respectively. At year-end 2011, the majority of total assets (92%) were in cash or investments, 100% of which were insured by the FDIC or SIPC. The board continues to review its investment guidelines but, to date, has opted to maximize safety over return in light of market volatility.

Note that in early 2012, BSF increased its research grant awards to $341,002, having been presented with a particularly promising set of proposals. In addition, 2012 is a conference year; additional expenses should be expected. Fundraising is expected to make up some portion of the deficit expected.

Statement of Financial Position

December 31, 2011 (with Comparative Totals for December 31, 2010)

ASSETS

	12/31/2011	12/31/2010
Assets:		
Cash and cash equivalents	$ 329,443	$ 538,826
Investments	1,499,571	1,401,337
Accounts receivable	163,351	89,369
Prepaid expenses	2,148	2,969
Total assets	**1,994,513**	**2,032,501**

LIABILITIES AND NET ASSETS

	12/31/2011	12/31/2010
Liabilities:		
Accounts payable and accrued expenses	19,302	23,062
Grants payable	80,000	76,980
Total liabilities	**99,302**	**100,042**
Net Assets:		
Unrestricted	937,779	1,063,759
Temporarily restricted	957,432	868,700
Total net assets	**1,895,211**	**1,932,459**
Total liabilities and net assets	**$ 1,994,513**	**$ 2,032,501**

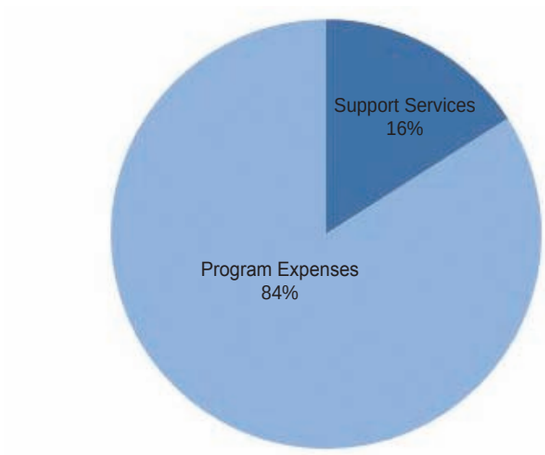
*See annual audit for notes and additional information

(Cont'd on page 10)

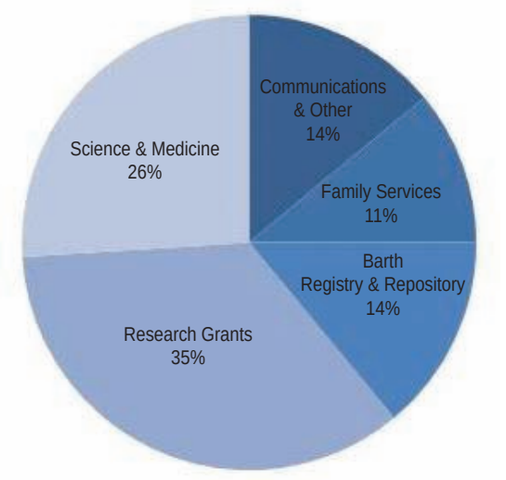
Statement of Activities

For the Year Ended December 31, 2011 (with Comparative Totals for the Year Ended December 31, 2010)

	Year Ended 12/31/2011	Year Ended 12/31/2010
PUBLIC SUPPORT AND OTHER REVENUES:		
Public Support:		
Contributions	$ 706,090	$ 729,756
	706,090	729,756
Investment Income	11,094	26,121
Unrealized Gain (Loss) on Investments	(1,766)	(746)
Total Public Support and Other Revenues	**715,418**	**755,131**
EXPENSES AND LOSSES:		
Program Services:		
Communications & Other	80,647	105,673
BSF Conference	7,833	202,655
Family Services	69,098	70,564
Barth Registry & Repository	88,901	89,185
Research Grants	262,115	277,968
Research Grants Funded Directly by BSFCa	(38,350)	(40,000)
Science & Medicine	164,629	156,334
	634,873	**862,379**
Supporting Services:		
Management & General	106,966	131,225
Development & Fundraising	10,827	33,388
	117,793	**164,613**
Total Expenses and Losses	752,666	1,026,992
CHANGE IN NET ASSETS	(37,248)	(271,861)
NET ASSETS, beginning of year	**1,932,459**	**2,204,320**
NET ASSETS, end of year	**$ 1,895,211**	**$ 1,932,459**



All Expenses



Breakdown of Program Expenses

Note: BSF's full 2011 audited financials are available on our website at: Home >> Legal Documents >> Annual Reports & Financials

LEADING THE WAY

The Barth Syndrome Foundation's Board of Directors assists with governance, fundraising efforts, and the overall guidance of BSF — while BSF's International Scientific & Medical Advisory Board offers expertise that is invaluable to the 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**		
BARTH SYNDROME FOUNDATION BOARD OF DIRECTORS		
Stephen McCurdy, Chairman	Michaela Damin, Board Member	Susan Osnos, Board Member
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David Axelrod, MD, Board Member	Susan McCormack, Board Member	John Wilkins, Board Member
Randy Buddemeyer, Treasurer	Katherine McCurdy, Board Member	Susan Wilkins, Board Member

BARTH SYNDROME FOUNDATION EXECUTIVE STAFF			
Lindsay Groff Executive Director	Shelley Bowen, Director Family Services & Awareness	Matthew Toth, PhD Science Director	Lynda Sedefian Executive Assistant

INTERNATIONAL AFFILIATES	
Barth Syndrome Trust *(UK & Europe)* Michaela Damin, Chair 1 The Vikings Romsey, Hampshire S051 5RG United Kingdom	**Barth Syndrome Foundation of Canada** Lynn Elwood, President 1550 Kingston Road, Suite 1429 Pickering, ON L1V 6W9 Canada
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

SCIENTIFIC & MEDICAL ADVISORY BOARD	
Michael Schlame, MD – Chairman Cell Biology & Anesthesiology, NYU School of Medicine, New York, NY, USA	Richard I. Kelley, MD, PhD Division of Metabolism, Kennedy Krieger Institute, Johns Hopkins University, Baltimore, MD, USA
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Miriam L. Greenberg, PhD Biological Sciences, Wayne State University, Detroit, MI, USA	Matthew J. Toth, PhD – *ex officio* BSF Science Director
Grant M. Hatch, PhD Lipid Lipoprotein Research, University of Manitoba, Winnipeg, Canada	

2011 DONORS

PAULA & WOODY VARNER FUND

Stars ($5,000+)

Dillon Foundation

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

Wilkins, Sue & Dr. Mike

General Contributions ($50 - $999)

Acklie Charitable Foundation
Allman, Peter & Maureen
Allman, Tom & Jane
Basler, Dr. Rod & Debbie
Beynon, Dave & Liz
Bingham, Dr. Dave & Kathy
Brehm, Russell & Louise
Buckley, Les & Nancy
Burmeister, Charles & Marita
Carveth, Dr. Steve & Beth
Cheatham, Linda
Farrar, Doug & Shawn Seacrest
Firestone, Dave & Jane
Ganz, Doug & Pam
Gelber, Dr. Ben & Elaine
Hedgecock, Norm & Debbie
Henricks, Dr. Bruce & Peggy
Kiechel, Dr. Fred
Linder, Dr. Max & Pat
Massengale, Dr. Martin & Ruth
Minnick, Gates & Daisy
Olson, Loy & Julie
Osborne, Dr. Tom & Nancy
Otte, Rob & Carolyn
Pittenger, Jim & Julie
Raun, Robert & Eileen
Rawley, Ann
Roskens, Ronald & Lois
Seaman, Andrew & Robyn Steely
Stohs, Dr. Gene & Kristen
Stuart, James & Susan
Stuckey, Dennis & Nancy
Tegt, Dr. Tom & Barb
Varner, Judy
Varner, Tom & Beth
Wilkins, Dr. Lee & Kristi
Wilkins, E. Joanne

SCIENCE & MEDICINE FUND

Stars ($5,000+)

Malkin,The Malkin Fund
McCurdy, Steve & Kate
Sernel, Marc & Tracy

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

Allen, John & Karen
Allen, Tiffini
Clark, Bob & Randy Galbreth
Heath, Amy
Kirkland & Ellis Foundation
Kugelmann, Peter
Kugelmann, Steve & Jan
Sedefian, Lynda
Ticche & Bea

SCIENCE & MEDICINE FUND

General Contributions ($50 - $999)

Barrett, James & Nancy
Campbell, Tonja
Galbreth, Randy & Betty
Harrigan, Timothy & Lori
IOPO Foundation, Inc.
Kiddin Around Downtown Daycare
Lloyd-Jones, Kimball & Mary
Newcomb, Suzanne
Pfizer Foundation Matching Gifts Program
Stenz, Jessica
Vendor Resource Management
Watson, Theda
Wayne, Alex

GENERAL FUND

Stars ($5,000+)

American Express Gift Matching
Buly, Dr. Robert & Lynne
Cusack, Tom & Carrie
The Frill Foundation
Grubb & Ellis
The Lebensfeld Foundation
Lummis, Ghent
Lummis, Marilyn
Lummis, William & Dossy
Malkin, Scott & Laura Malkin SL 2005Family Trust
McCurdy, Steve & Kate
McKown, Christopher & Abigail Johnson
Pierson, Dr. Richard & Allene
Russell, Allene & Paul Russell Fund
Sernel, Gordon & Sharon

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

American Express PAC Match
Anonymous
Arquit, Kevin
Barad, Seth & Amy
BBM Group LLC
Buddemeyer, Randy
Drake, Bryan
Evoy, Larry & Sally
Fowler, Susan & David Fowler Charitable Gift Foundation
Glenn, William H.
Grose, Madison & Nora
Hales, Bryan & Holly
Hsieh, David
Ingersoll, Ann
Johnson, Malcolm & Deloris
Kavetas, Harry L. Kavetas Family Fund
Kearns, Richard & Kathleen
M.C. Dean, Inc.
Malkin, Louisa Rice Malkin Fund
Malkin, Rebecca Swift Malkin Fund
Mann, Allen & Rosa
Matelich, George & Susan
McCormack, Susan
McCurdy, Chris & Kris
McCurdy, William & Virginia
Miller, Kirt & Martha
Minor, Walter & Eleanor
Osnos, Susan & Peter
Randolph, Dr. Peter & Helen
Renaissance Charitable Foundation
Stoll, Ned & Cindy
Tortimaki Foundation
Vaisman, Natan & Beth Roberts
Winston, Laura

GENERAL FUND

General Contributions ($50 - $999)

Abbonizio, Leita
Adelson, Robin
Alcabes, Elisa
Alderman, Thomas & Lisa
Allan, Julia
Ameriprise Employee Gift Matching
Ames, Kathleen
Andrews Trust
Aurely, Philip
Axelrod, Dr. David & Jessica
Azar-Kuhn, Laura
Baffa, Ted & Rosemary
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"I watched and witnessed their hope, sacrifice, love, and care. When I looked at their son, my heart overflowed with joy and hope. I had an urge to want to fight for him, to stand up for him, to pray for him ..." *Ashley Cade, Volunteer, St. Louis, MO*

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

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- Increase family participation in Barth Registry & Repository
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- Help develop effective treatments
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