

# Barth Syndrome Foundation



*Photos courtesy of BSF*



Barth Syndrome  
Foundation

[www.barthsyndrome.org](http://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*

## TABLE OF CONTENTS

|                                  |       |
|----------------------------------|-------|
| Chairman's Message.....          | 3     |
| Education & Support              |       |
| Awareness.....                   | 4     |
| Family Services.....             | 5     |
| Family Outreaches.....           | 6     |
| Science & Medicine               |       |
| Barth Registry & Repository..... | 7     |
| Research.....                    | 7-8   |
| Finances.....                    | 9-10  |
| Leadership.....                  | 11    |
| Donors.....                      | 12-13 |
| Time & Advice.....               | 14    |
| Mission, Goals, Values.....      | 15    |
| Call to Action.....              | 16    |

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.

A handwritten signature in black ink that reads "Stephen B. McCurdy". The signature is written in a cursive, flowing style.

# 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.”***

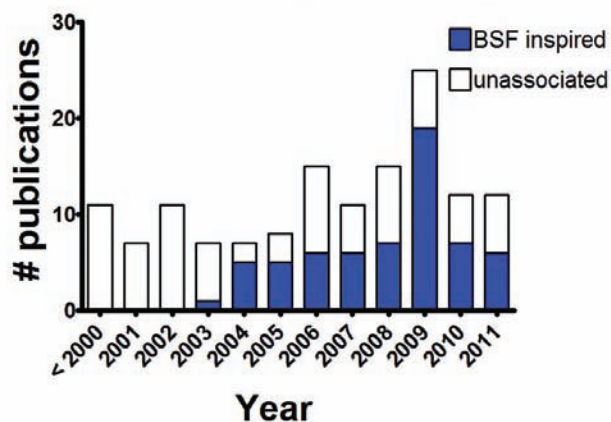
*W. Todd Cade, PT, PhD*



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).

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

### BTHS related publications



(Pubmed search terms: Barth syndrome, tafazzin)

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.

Milosh



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](#).

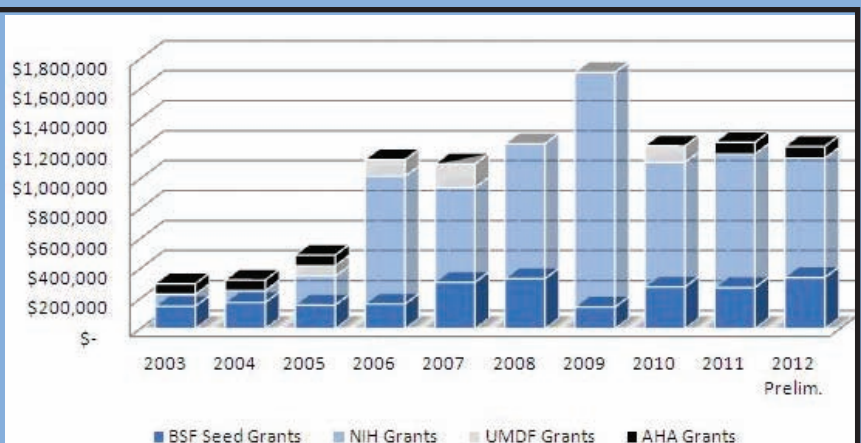
| 2011 Grant Awardees  |  |
|--|--|
|  <p>Steven M. Claypool, PhD, Johns Hopkins University, Baltimore, MD, USA</p> <p><b>Characterizing endogenous mammalian TAZ1</b></p> <p>Award — US \$40,000 over 1-year period</p>  |  <p>Grant Hatch, PhD, University of Manitoba, Winnipeg, Manitoba, Canada</p> <p><b>MLCL AT-1 elevates cardiolipin and mitochondrial function in cardiac myocytes of taz knockdown mice</b></p> <p>Award — US \$40,000 over 1-year period**</p>            |
|  <p>William T. Pu, MD, Children's Hospital of Boston, Boston, MA, USA</p> <p><b>Using induced pluripotent stem cells and modified RNAs to model and correct BTHS</b></p> <p>Award — US \$40,000 over 1-year period</p>  |  <p>Yana Sandlers, PhD, Kennedy Krieger Institute, Baltimore, MD, USA</p> <p><b>Characterization of biochemical abnormalities in BTHS patients and mouse model of BTHS.</b></p> <p>Award — US \$21,065 over 1-year period</p>                             |
|  <p>Mindong Ren, PhD, New York University School of Medicine, New York, NY, USA</p> <p><b>Drug repositioning for BTHS</b></p> <p>Award — US \$40,000 over 1-year period</p>  |  <p>Ji Zhang, MD, PhD, University of California at San Diego, San Diego, CA, USA</p> <p><b>Functional characterization of a mitochondrial lipid phosphatase that involves cardiolipin biosynthesis</b></p> <p>Award — US \$40,000 over 2-year period</p> |
|  <p>Miriam Greenberg, PhD, Wayne State University, Detroit, MI, USA</p> <p><b>Cardiolipin deficiency leads to defects in the TCA cycle</b></p> <p>Award — US \$40,000 over 1-year period*</p>   |  <p>Junhwan Kim, PhD, Case Western Research University, Cleveland, OH, USA</p> <p><b>Causative and correlative role of cardiolipin on integrated mitochondrial function in BTHS</b></p> <p>Award — US \$40,000 over 1-year period</p>                   |
|  <p>W. Todd Cade, PT, PhD, Washington University School of Medicine, St. Louis, MO, USA</p> <p><b>Effects of resistance training on cardiac, metabolic, and muscle function and quality of life in BTHS</b></p> <p>Award — US \$39,937 over 1-year period</p> | <p>*Funding for this award was provided by Association Barth France.</p> <p>**Funding for this award was provided by BSF of Canada.</p>  |

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       |
|---------------------------|------------------|------------------|
| <b>Assets:</b>            |                  |                  |
| 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            |
| <b>Total assets</b>       | <b>1,994,513</b> | <b>2,032,501</b> |

### LIABILITIES AND NET ASSETS

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

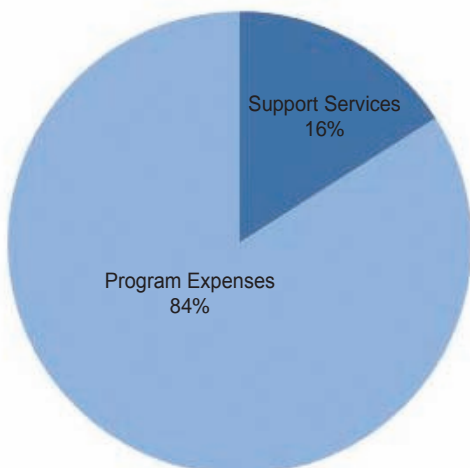
\*See annual audit for notes and additional information

(Cont'd on page 10)

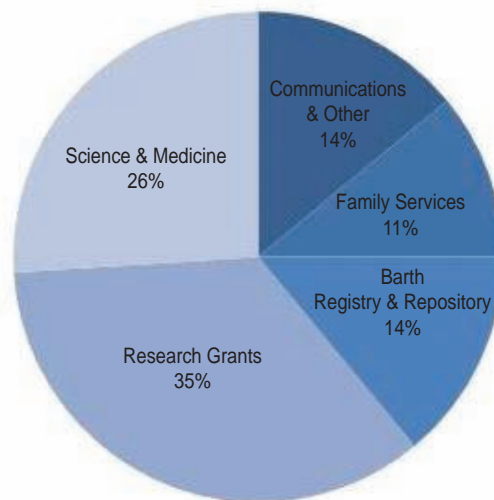
# Statement of Activities

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

|   | Year Ended<br>12/31/2011 | Year Ended<br>12/31/2010 |
|---|--------------------------|--------------------------|
| <b>PUBLIC SUPPORT AND OTHER REVENUES:</b> |                          |                          |
| Public Support:                           |                          |                          |
| Contributions                             | \$ 706,090               | \$ 729,756               |
|   | <u>706,090</u>           | <u>729,756</u>           |
| Investment Income                         | 11,094                   | 26,121                   |
| Unrealized Gain (Loss) on Investments     | ( 1,766)                 | ( 746)                   |
|   | <u>715,418</u>           | <u>755,131</u>           |
| <b>EXPENSES AND LOSSES:</b>               |                          |                          |
| 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                  |
|   | <u>634,873</u>           | <u>862,379</u>           |
| Supporting Services:                      |                          |                          |
| Management & General                      | 106,966                  | 131,225                  |
| Development & Fundraising                 | 10,827                   | 33,388                   |
|   | <u>117,793</u>           | <u>164,613</u>           |
| Total Expenses and Losses                 | <u>752,666</u>           | <u>1,026,992</u>         |
| <b>CHANGE IN NET ASSETS</b>               | <u>( 37,248)</u>         | <u>( 271,861)</u>        |
| <b>NET ASSETS, beginning of year</b>      | <u>1,932,459</u>         | <u>2,204,320</u>         |
| <b>NET ASSETS, end of year</b>            | <u>\$ 1,895,211</u>      | <u>\$ 1,932,459</u>      |



**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<br>PO Box 618<br>Larchmont, NY 10538 |                                 |                                    |
|--|---------------------------------|------------------------------------|
| BARTH SYNDROME FOUNDATION BOARD OF DIRECTORS                   |                                 |                                    |
| Stephen McCurdy, Chairman                                      | Michaela Damin, Board Member    | Susan Osnos, Board Member          |
| Lindsay Groff, <i>ex-officio</i> , Executive Director          | Stephen Kugelmann, Board Member | Marcus Sernel, Corporate Secretary |
| 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<br>Executive Director       | Shelley Bowen, Director<br>Family Services & Awareness | Matthew Toth, PhD<br>Science Director | Lynda Sedefian<br>Executive Assistant |

| INTERNATIONAL AFFILIATES  |   |
|---|---|
| <b>Barth Syndrome Trust (UK &amp; Europe)</b><br>Michaela Damin, Chair<br>1 The Vikings<br>Romsey, Hampshire S051 5RG<br>United Kingdom | <b>Barth Syndrome Foundation of Canada</b><br>Lynn Elwood, President<br>1550 Kingston Road, Suite 1429<br>Pickering, ON L1V 6W9<br>Canada |
| <b>Barth Trust of South Africa</b><br>Jeannette Thorpe, Chair<br>49 Abelia Road<br>Kloof, Pinetown<br>3610 Natal<br>South Africa        | <b>Association Barth France</b><br>Florence Mannes, Chair<br>12, rue Lalo<br>75116 Paris<br>France  |

| SCIENTIFIC & MEDICAL ADVISORY BOARD  |  |
|--|--|
| Michael Schlame, MD – Chairman<br>Cell Biology & Anesthesiology, NYU School of Medicine,<br>New York, NY, USA                                | Richard I. Kelley, MD, PhD<br>Division of Metabolism, Kennedy Krieger Institute,<br>Johns Hopkins University, Baltimore, MD, USA |
| Peter G. Barth, MD, PhD – <i>Emeritus</i><br>Pediatric Neurology (retired), Emma Children's Hospital / AMC,<br>Amsterdam, The Netherlands    | Colin G. Steward, PhD, FRCP, FRCPCH<br>Pediatric Hematology, Royal Hospital for Children, Bristol,<br>England                    |
| Barry J. Byrne, MD, PhD<br>Pediatric Cardiology, Shands Children's Hospital, University of<br>Florida, Gainesville, FL, usa                  | Jeffrey A. Towbin, MD<br>Pediatric Cardiology, Cincinnati Children's Hospital,<br>Cincinnati, OH, USA                            |
| Gerald F. Cox, MD, PhD<br>Clinical Genetics, Children's Hospital Boston, Boston, MA;<br>Clinical Research, Genzyme Corp., Cambridge, MA, USA | Ronald J. A. Wanders, PhD<br>Genetic Metabolic Diseases, Academic Medical Center,<br>Amsterdam, The Netherlands                  |
| Iris L. Gonzalez, PhD<br>Molecular Diagnostics Lab ( <i>retired</i> ), A. I. DuPont Hospital for<br>Children, Wilmington, DE, USA            | Katherine R. McCurdy – <i>ex officio</i><br>BSF Board Member   |
| Miriam L. Greenberg, PhD<br>Biological Sciences, Wayne State University, Detroit, MI, USA  | Matthew J. Toth, PhD – <i>ex officio</i><br>BSF Science Director   |
| Grant M. Hatch, PhD<br>Lipid Lipoprotein Research, University of Manitoba, Winnipeg,<br>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  
IOPF 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  
Lumms, Ghent  
Lumms, Marilyn  
Lumms, William & Dossy  
Malkin, Scott & Laura Malkin  
SL 2005 Family Trust  
McCurdy, Steve & Kate  
McKown, Christopher & Abigail Johnson  
Pierson, Dr. Richard & Allene  
Russell, Allene & Paul Russell Fund  
Semel, 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  
Baffa, Estate Of Theodore Baffa  
Ballard, Stacey H.  
Bartels, Kenneth & Jane  
Bashforth, Paul  
Bateman, Cynthia  
Bater, Jennifer N.  
Bell, Desmond  
Bennett, Claudia  
Bennis, Lisa  
Berger, Samuel & Trisanne Berger Family Charitable Gifts  
Berland, Jonathan & Leslie  
Berry, Rick & Carla  
Bertan, David  
Blake One Inc.  
Bodary, Michael & Lisa  
Bogage, Judith  
Bogert, Amy  
Bogert, Carroll  
Bogert, Nicholas & Sally  
Boland, William & Lisa  
Bond, Louis & Kimberly  
Bornstein, David  
Bradley, Dr. Carl  
Bradley, Robert & Margaret  
Brause, David  
Brenner, Andrew & Kathleen  
Brody, D.W. & Tracy  
Brown, Wendy  
Bucci, Michael & Erika  
Buddemeyer, Carl & Donna  
Buddemeyer, Leslie  
Burke, Margaret  
Burns, Geraldine  
Burtis, Cleo  
Butler, David & Cherryh  
Calabrese, Frederick & Anne  
Calabrese, Joanne  
Canal, Joseph & Annette  
Capone, Anthony  
Cappello, Frances  
Carney, Catherine  
Cavanaugh, Matthew & Alice  
CCMH Auziliary Gift Shop  
Chandler, Robert & Darla  
Chapin, Stephen & Debbie  
Charendoff, Susan  
Charles Cole Memorial Hospital  
Cherniak, Benjamin  
Chin, Elaine  
Church, Charlotte  
Citta, Laura  
Clapp, John & Irene  
Cleary, Michael & Jamie  
Cleek, Robin  
Cohen, Loren  
Community Health Charities of California  
Concannon, Richard & Maura  
Conkling, Nancy  
Cordon, Jr., Santos  
Cracchiolo, James & Marilyn  
Crowley, Chuck & Diane  
Cunniffe, Peter & Jodi  
Cushmore Family  
Dannels, Richard & Therese  
DeAngelo, Suzanne  
DeBaker, Robert  
Delphais, Frank & Pamela  
DeMillion, John & Kelly  
Diaz, Karen  
Divalerio, Renee  
Divon, Ronen  
Doherty, James & Kimberly  
Donnalley, Jennifer  
Drake, Frank & Teresa  
Draper, Steve  
DuHamel, Constance  
Duran, Lisa Garcia  
Durso, Francesco  
Edelman, Jay  
Elko, Charlotte  
Elliott, Christine  
Epstein, Paul & Leah  
Excela Health Latrobe Hospital  
ExecComm LLC  
FABTrends International  
Fagan, Bill & Constance  
Falk, Linda  
Farrell, Tim & Susan  
Fasman, Steven  
Faxon, Kevin & Susan  
Feldman, Deborah  
Feldman, Richard & Rosalyn  
Field, Michael & Kathleen  
Filby, Linda  
Fiore, Susan  
Firestone, Jim & Ann  
Fitzgerald, Elizabeth  
Floyd, Ed & Julie  
Flynn, Clare Stenson  
Forsyth, John  
Franklin, Peter & Dorothy  
Freidus, Dahna  
Fuller, Jim & Barbara  
Gallagher, James & Mary Jane  
Garcia, Michelle  
Garrett Hill Auto Service, Inc.  
Garry, Bobby & Leigh  
Gates, Bill & Melinda Gates Foundation  
Geithner, Peter & Deborah  
Gellman, Richard & Jennifer  
Gerfen, Henry  
Gerspach, Eileen  
Gerszberg, Richard  
Girsky, Laurie  
Golden, Michael  
Goodman, Carol  
Goodwin, William & Virginia  
Gorman, James  
Gottdiener, Karen  
Gottsegen, Alison  
Graham, Megan  
Gray, Donald & Virginia  
Greene, Jeremy  
Greene, Rev. Dorothy  
Grossman, Dr. Harvey  
Gungor, Umut  
Guyer, Doug & Jann  
Hagan, John & Christine  
Halloran, John  
Hamill, Charles & Jo

Hammett, Kathy  
 Harman, James & Merlene  
 Hartel, Charles  
 Hayes, Edward  
 Haynard, Ed  
 Hazen, Ned & Liz  
 Healey, Christine  
 Heaton, Seth  
 Heering, Lori  
 Heine, Timothy  
 Heineman, Cristine  
 Heinsinger, Robert & Mary Lou  
 Henricks, Dr. Bruce & Peggy  
 Hepp, Timothy  
 Herr, Katherine V.  
 Hidden, Jr., Bob & Ann  
 Higgins, Thomas  
 Hinchcliffe, Brian & Carol  
 Hobbins, Antonia  
 Holbrook, Frank  
 Holly, Greg  
 Holly, Peggy M.  
 Holt, Mandy  
 Howell, David & Patricia  
 Hubby, Pamela  
 Hubert, Mary  
 Ichel, David  
 If It's Water, Inc.  
 Irving, John & Emily  
 Itzkowitz, Lisa  
 Jaimes, Eneida  
 Janiec, Stephen & Diane  
 Janus Foundation  
 Jarrett, Catherine  
 Jofre, Jaime  
 Johnson, Richard  
 Joyce, Winifred H.  
 Julie, Franklin  
 Kahler, Timothy & Judith  
 Kahn, Michael  
 Kalapasev, Nenad  
 Karow, Elyse  
 Karp, Jane  
 KBR Community Matching Gifts  
 KCSA Worldwide  
 Kealey, Patrick & Mary Jane  
 Kearney, Andrew & Maureen  
 Kelly, Raymond  
 Kennedy, Jason & Jarrah Rochelle  
 Kimberlin, Kevin & Joni  
 Kimos, Irina  
 Kirkham, Collier & Ann  
 Kline, Christy  
 Klockner, Daniel & Nancy  
 Knopp, Cheryl  
 Knopping, Jeffrey J.  
 Kole, Walter & Catherine  
 Kornweiser, Leslie  
 Kreisberg, Amy  
 Kugelmann, Steve & Jan  
 Kuhl, Phillips & Karen  
 Lancaster, George  
 Lankler, Jill  
 Layton, Alanna  
 Lederman, Dr. Seth & Sarah  
 Lee, Dongho  
 Lenni Lenape Girl Scout Council  
 Leon, Susan

Lettrich, Robert  
 Levinson, Marla  
 Liebenguth, Marilyn D.  
 Liebman, David  
 Lipson, Matthew  
 Liscio, Mark & Elizabeth  
 Little Tykes Therapy  
 Long, Randall & Maya  
 Lowenthal, Daniel & Naomi  
 Lummis, Palmer & Mallory  
 Maca, Sarah  
 MacKay, Doug  
 Madden, Margaret  
 Mailman, Dorrie  
 Mancino, Angelo & Rosemary  
 Mann, David & Shelia  
 Marks, Michael & Cynthia  
 Marshall, Richard  
 Massimo, Anthony & Mary Elizabeth  
 Matarazzo, Giovanna  
 Matusow, Randy  
 Mayers, Bruce  
 McCaughan, Sean & Jeannette  
 McClintock, Michael & Cynthia  
 McDonough, Jay Michael & Donna  
 McEvily, Michael  
 McFee, Wendy & Jmel Wilson  
 McHugh, George & Margaret Ann  
 McKay, Richard  
 McKenzie, Eileen  
 McLaughlin, William & Sheila  
 McTear, John & Donna  
 Meltzer, Anne  
 Meyer, James  
 Michaud, Steven & Yoko  
 Miller, Jane Esther  
 Miller, Jill  
 Miller, Richard & Lynne  
 Millman, Paul & Susan  
 Minniti, Suzanne  
 Mixer, Stephen & Elizabeth  
 Monahan, Tom & Laurie  
 Montanaro, Louis & Theresa  
 Morehouse, Clark & Susan  
 Motzkin, Robert  
 Mueller, Carl & Suzanne  
 Mulhern, Jr., Robert  
 Munson, Elizabeth  
 Murawski, Michael  
 Naugler, Danielle  
 Neff, Elizabeth  
 Nichols, Bill & Chris  
 Nicoll, Thomas & Mary  
 Odouard, Francois  
 Olson, Ken & Tina  
 Olson, Nicole  
 Orso, John & Theresa  
 Osnos, Evan & Sarabeth  
 Osterhaus, Greta  
 Ott, Pearl  
 Paolizzi, Vincent & Celeste  
 Papone, Aldo & Sandra  
 Parent, Louise  
 Parlato, Charles & Carolyn  
 Pattee, Diane  
 Pepworth, Donna  
 Perez, Alan & Heather  
 Perlman, Robin

Perri, Jason  
 Peterson, Carl & Andrea  
 Pfizer Foundation Matching Gifts Program  
 Pierce, Frederick & Lorraine  
 Pierson, Frank & Nancy  
 Pineault, Mitch  
 Plonsker, Robin  
 Plumez, Jean Paul & Jacqueline  
 Polak, Jennifer  
 Porter, Tim & Carla  
 Prato Fiorito, Anthony  
 Purcell, Bob & Jackie  
 Putnam Investments  
 Puzio, Martin & Donna  
 Rader, Carol  
 Radio Computing Services Charitable Foundation  
 Raftery, John  
 Rager, Meda  
 Ramanathan, Sreeram  
 Ratner, Ian & Carol  
 Recco, Gerald & Madeline  
 Reeder, Adam & DeAnnie  
 Reid, Colin  
 Rey, Lisa M.  
 Rigsby, Robert & Deborah  
 Ritchea, Shery  
 Rivers, Timothy & Dori  
 Roberts, John & Betty  
 Robidoux, Monique  
 Robinson, Francis & Sharon  
 Robinson, Rebecca  
 Rodan, Amnon & Dr. Katie  
 Rodbell, Gary & Colette  
 Rodbell, Mitchell & Liz  
 Rogers, Larry & Catherine  
 Rosenblatt, Stephen  
 Rothschild, Adam & Kathy  
 Rotondi, Andrew & Mary Frances  
 Rozansky, Marc & Sherri  
 Rush Truck Centers  
 Russell, Nat & Becky  
 Russell, Dr. Nina & Tom Rubin  
 Russell, Gregory & Charlotte  
 Russell, Harold & Margo  
 Sadler, Evelyn  
 Sams, Louise  
 Sanborn, Noel  
 Sandoval, Claudio & Ellen Marie  
 Santry, Aine  
 Sarkozi, Paul & Jill  
 Schifman, Jennefer  
 Schoen, Christopher & Melissa  
 Schreiter, Karl & Margaret  
 Schroeder, Melissa  
 Schwartz, Mark & Marie  
 Scmitt, Emilie  
 Osterhaus, Greta  
 Segal, Anne  
 Segal, Mark & Heather  
 Sellet, Rebecca  
 Serzan, Vincent & Eileen  
 Shearer, Deidre  
 Shek, Anthony  
 Shephard, Greg  
 Sherer, Peter & Marilu  
 Shilobod, Vincent & Kim  
 Shipley, William

Shirley, William & Catherine  
 Siegal, Laura  
 Sims, David & Jennifer  
 Sisters Of St. Francis  
 Slone-Goldstein, Tara  
 Smith, Camille  
 Snedeker, Robert & Frances  
 Sons Of The American Legion Post 305  
 Sorrento, Nora  
 Spangle, Laurie  
 Spotts, Dr. Jules  
 St. Louis Country Treasurer  
 Standley, Burgess & Caroline  
 Stanton, Gregory & Maria  
 Staub, Amy  
 Stein, Kerry  
 Steinberg, Jack  
 Stenson, Martin & Marie  
 Stenson, Michael  
 Stevenson, Robert & Sharon  
 Strauss, Judith  
 Stuhlfreyer, Tom & Kim  
 Sullivan, William & Barbara  
 Svaty, Rachel  
 Swennen, Erik & Veerle  
 The Black Dog Private Foundation  
 Theisen, Theodore & Carrie  
 Thomas, Marion  
 Thomas, Matthew  
 Thompson, Kurt & Marybeth  
 Toth, Dr. Matthew & Marilyn  
 Tulchin, David & Nora  
 Tyndall, Kathleen  
 United Way of Central & North-eastern CT  
 Vail, William  
 Varnell, Ben & Ivadell  
 Viebranz, Elaine  
 Vogt, Jerre  
 Wadel, Nancy  
 Waite, Joel & Mary Frances  
 Waters, Marty & Helen  
 Wechsler, Daniel  
 Weinstein, Wendy  
 Welcome, Michael & Carolyn  
 Weltlich, Robert & Dodie  
 Weltlich, Steve & Sharon  
 Wenglin, Dr. Barry & Barbara  
 White, Johnny & Joyce  
 White, Mickey & Sharon  
 White, Vanessa  
 Whitt, Karen  
 Wilkov, Marcy E.  
 Williams, Kathleen  
 Wischnowski, Stan & Shawn  
 Wong, Kityen  
 Wynia, Brent & Shari  
 Zado, Erica  
 Zeitner, Eric  
 Zierk, Holly  
 Zierk, Tom & Gail  
 Zoland, Yale & Wendy

It is only through the support of family, friends, and caring donors  
 that we will be able to steadfastly continue to work toward the Foundation's vision.  
 We appreciate your support and generosity.

# 2011 ~ TIME & ADVICE

## TIME & ADVICE

Abel, Dr. E. Dale  
 Abeliovich, Hagai  
 Abrahams, Esq., Beth Polner  
 Acehan, Dr. Devrim  
 Adihetty, Dr. Peter  
 Agellon, Dr. Lou  
 Ahmad, Dr. Ferhaan  
 Andersen, Harold  
 Anderson, Wayne & Suzie  
 Aprikyan, Dr. Andrew  
 Artman, Dr. Michael  
 Axrelrod, Dr. David  
 Azar Kuhn, Laura  
 Bader, Michael  
 Baffa, Rosemary  
 Bakovic, Dr. Marica  
 Bargo, PT, Jennifer  
 Barth, Dr. Peter  
 Bazinet, Dr. Richard  
 Becker, Dr. Catherina G.  
 Beh, Dr. Christopher  
 Bellamy, Amanda  
 Bennett, Dr. Michael  
 Benni, Dr. Paul  
 Berry, Dr. Gerald T.  
 Beulow, Nancye  
 Beyer-Lead, Rick  
 Bolyard, RN, Audrey Anna  
 Bowen, Shelley  
 Bowron, Ann  
 Breitinger, PA, Petar  
 Bryant, Dr. Randall M.  
 Buddemeyer, Randy  
 Bullitt, Dr. Esther  
 Bungert, Dr. Jorg  
 Bütikofer, Dr. Peter  
 Byrne, Dr. Barry J.  
 Cade, Ashley  
 Cade, Dr. W. Todd  
 Callahan, Lynn  
 Carboni, Dr. Michael  
 Carney, Janet  
 Carter, Kate Casidine  
 Chase, Kevin  
 Chicco, Dr. Adam J.  
 Chrisant, Dr. Maryanne  
 Christie, Dr. William W.  
 Chu, Dr. Charleen T.  
 Clay, Donna  
 Claypool, Dr. Steven M.  
 Clayton, Nicol  
 Cockcroft, Prof. Shamshad  
 Congenital Cardiology Today  
 Corley, Marion  
 Cortez, Anne  
 Cox, Dr. Gerald F.  
 Crain, Carrie  
 Dahlberg, Dr. Martin  
 Dale, Dr. David  
 Damin, Michaela  
 Dancis, Dr. Andrew  
 Daum, Dr. Guenther  
 Davies, Rob  
 Davis, Anastasia  
 de Koning, Dr. T.J.  
 De Kroon, Dr. Anton I.  
 Des Rosiers, Dr. Christine  
 Dingli, Dr. David

Dowhan, Dr. William  
 Drinkwater, Paul  
 Duncan, CPA, Peter  
 Elwood, Lynn  
 Epand, Dr. Richard M.  
 Epstein, Paul  
 Fan, Dr. Yuxin  
 Fei, Naomi  
 Fleischmann, Dr. Bernd  
 Flotte, Dr. Terence R.  
 Floyd, Julie  
 Flynn, Clare  
 Fortier, Jodie  
 Foxon, Kim  
 Fricker, Dr. Jay Frederick  
 Frohman, Dr. Michael  
 Funke, Dr. Birgit  
 Gagnon, Lou Ann  
 Gaudin, Herve  
 Gelb, Dr. Bruce D.  
 Germeshausen, Dr. Manuela  
 Gerszberg, Rich  
 Gerull, Dr. Brenda  
 Geva, Judith  
 Gill, Carrie  
 Giulivi, Dr. Cecilia  
 Gohil, Dr. Vishal M.  
 Goodman, Dr. Beverly  
 Gonzalez, Dr. Iris L.  
 Gottlieb, Dr. Eyal  
 Greenberg, Dr. Miriam L.  
 Groff, Lindsay  
 Groft, Dr. Stephen C.  
 Haines, Dr. Thomas H.  
 Hammond, Dr. H. Kirk  
 Han, Dr. Xianlin  
 Hardison, Haille & Jodi  
 Harford, Greg  
 Harford, Larry  
 Harley, Elma Rhea  
 Harrington, Hon. James  
 Hastings, Dr. Rob  
 Hatch, Dr. Grant M.  
 Haucke, Dr. Volker  
 Hawkins, Lawton  
 He, Dr. Quan  
 Heal, Elisabeth  
 Henry, Anne  
 Henry, Dr. Susan A.  
 Higgins, John & Liz  
 Hope, Chris  
 Hope, Michael  
 Hoppel, Dr. Charles  
 Horwitz, Dr. Marshall S.  
 Houtkooper, Dr. Riekelt  
 Jacob, BS, Marni L.  
 Jefferies, Dr. John Lynn  
 Jensen, Dr. Robert E.  
 Jofre, Jaime  
 Johnson, Kristen  
 Johnson, Linda  
 Johnston, Dr. Jennifer J.  
 Joshi, Amit S.  
 Kacinski, Debbie  
 Kainer, Daryl  
 Karp, Matt  
 Karp, Wendy  
 Kaufman, Dr. Beth D.  
 Kelley, Dr. Richard I.

Keyser, Dr. Randall E.  
 Khuchua, Dr. Zaza  
 Kiebish, Dr. Michael A.  
 Kim, Dr. Junhwan  
 King, Lynn  
 Kirwin, Susan M.  
 Klionsky, Dr. Daniel J.  
 Koehler, Dr. Carla  
 Knopping, Jeff  
 Koeberl, Dr. Dwight D.  
 Koehler, Dr. Carla  
 Kowalczyk, Randy  
 Kreider, MHS, OTR/L, Consuelo  
 Kropp, Susan  
 Kugelman, Steve  
 Kuhlbrandt, Dr. Werner  
 Kuijpers, Dr. Taco  
 Kulik, Dr. Willem  
 Lamb, Dr. Richard  
 Lamoia, Michelle  
 Lane, Anna  
 Lallemand, Madeleine  
 Langer, Dr. Thomas  
 Lawson, Lee Ann  
 Leça, Dr. Ana  
 Lenaz, Dr. Giorgio  
 Levin, Dr. Gail  
 Lewin, Dr. Alfred S.  
 Liang, Dr. Hanyu  
 Lipshultz, Dr. Steven E.  
 Lohmann, Jessica  
 Lopes, Dr. John M.  
 Lowe, DHSc, PT, Jodi  
 Lucas Productions  
 Lummis, Ghent  
 Lyall, Doug  
 Lynn, John  
 Madgett, Roberts, Marlowe,  
 Jackson & Associates  
 Malhotra, Dr. Ashim  
 Mann, Shelia  
 Mannella, Dr. Carmen  
 Mannes, Florence & Philippe  
 Manton, Annick  
 Margossian, Dr. Renee  
 Marra, Ken  
 Martin, Joy  
 Martins, Raquel  
 Maruno, Yuriko  
 Matthias, Linda  
 Mazzocco, Dr. Michele  
 McClellan, MGC, Rebecca  
 McConaughy, Jim & Bev  
 McCormack, Susan  
 McCurdy, Eliza  
 McCurdy, Kate  
 McCurdy, Steve  
 McCurdy, Will  
 McKown, Chris  
 McMaster, Dr. Christopher  
 Miller, Cheryl  
 Mitchell, Jim  
 Mochel, Dr. F.  
 Mock, Kim  
 Monetti, Kayleigh  
 Montenero, Theresa  
 Moore, Lorna  
 Moore, Nigel  
 Moore, Dr. Russell L.

Morava, Eva  
 Moreno-Quinn, Dr. Carol  
 Morris, Les  
 Murphy, Tony  
 Nackashi, Dr. John  
 Nixon, RN, Connie  
 Nobrega, Marcelo A.  
 Ntambi, Dr. James  
 Nunnari, Dr. Jodi  
 Oberst, Dr. Andrew  
 Odouard, Francois  
 Orstavik, Dr. Karen  
 Osnos, Susan  
 Pan, Dr. Yong  
 Patil, Vinay A.  
 Payne, Dr. R. Mark  
 Perkins, Phyllis  
 Phoon, Dr. Colin K.  
 Pilitowski, Bill & Colleen  
 Pittman, Jackie  
 Porter, Dr. George  
 Pruet, Debbie  
 Pu, Dr. William  
 Radosta, Lori  
 Reece, Bryce  
 Ren, Dr. Mindong  
 Reppen, Heather  
 Reynolds, Dr. Stacey  
 Rigney, John  
 Ristow, Dr. Michael  
 Rivkees, Dr. Scott A.  
 Rizzo, Dr. William  
 Roberts, Dr. Amy  
 Rodbell, Gary  
 Rodbell, Colette & Julia  
 Rodenburg, Dr. R.J.T.  
 Ros, Dr. Joaquim  
 Roubos, Mr. & Mrs.  
 Ryan, Jane  
 Ryan, Dr. Mike  
 Saidi, Dr. Arwa  
 Saric, Dr. Tomo  
 Mannes, Florence & Philippe  
 Sandler, Dr. Yana  
 Saroyan, Dr. John  
 Schantzen, Sandy  
 Schlame, Dr. Michael  
 Schlessinger, Dr. Avner  
 Schrader, Cherie  
 Schroeder, Dr. E. Todd  
 Schroeder, Wallace & Alexis  
 Segal, Heather  
 Segui, Damaris  
 Senthilnathan, Selvi  
 Sernel, Marc  
 Sheppard, Jamie  
 Sherbany, Dr. Ariel  
 Sherman, Cathy  
 Sherwood, Dr. Geoff  
 Shi, Dr. Yuguang (Roger)  
 Shih, Dr. Renata  
 Shindou, Dr. Hideo  
 Shirley, Alan & Denise  
 Shum, Bill & Ginny  
 Slaughaupt, Dr. Susan A.  
 Smith, Deborah  
 Smithson, Sarah  
 Smolski, Ed  
 Smoot, Dr. Leslie

Snyder, Floyd  
 Somerharju, Dr. Pentti  
 Soustek, Meghan S.  
 Sparagna, Dr. Genevieve  
 Spencer, Dr. Carolyn T.  
 Stanford, RN, Dianne  
 Stark, Dr. Ruth E.  
 Stehno-Bittel, Dr. Lisa  
 Steinberg, Jack  
 Steward, Dr. Colin G.  
 Stewart, Mr. & Mrs. Michael  
 Straits, Brian & Jan  
 Strauss, Dr. Arnold W.  
 Sullivan, Melissa  
 Sutphin, Dr. Robert M.  
 Sydnor, Laurie  
 Taegtmeier, Dr. Heinrich  
 Tarnopolsky, Dr. Mark  
 Taylor, Damani  
 Thomas, Carla  
 Thompson, Angie  
 Thompson, Erin  
 Thorburn, Dr. David  
 Thorpe, Jeannette  
 Titorenko, Dr. Vladimir  
 Towbin, Dr. Jeffrey A.  
 Townsend, Esq., Colyn  
 Tsai-Goodman, Dr. Beverly  
 Tunguz, Stefan  
 Tweed, Scott  
 Rivkees, Dr. Scott A.  
 van der Riet, Hans  
 van Ommen, Dr. Gert-Jan B.  
 van Raam, Dr. Bram J.  
 Vancura, Dr. Ales  
 Vaz, Dr. Frédéric M.  
 Ventura-Clapier, Dr. Renee  
 Vosgien, Don  
 Walker, Gena  
 Walsh, Dr. Craig  
 Wanders, Dr. Ronald J. A.  
 Weltlich, Dodie  
 Whebble, Pam  
 White, Marty  
 Wicker, Judy  
 Wiggins, Mark  
 Wilkins, John  
 Wilkins, Sue  
 Wilks, Carol  
 Williams, Kathy  
 Wilson, Dr. Lori D.  
 Wise, Lisa  
 Wood, Robin  
 Wroe, Martha  
 Wu, Dr. Joseph C.  
 Wu, Dr. Sean M.  
 Xiao, Dr. Xiao  
 Xu, Dr. Yang  
 Ye, Dr. Zhaohui  
 Zaragoza, Dr. Michael  
 Zhang, Dr. Ji  
 Zhang, Shali  
 Zhou, Dr. Bin

"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*

## 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."***

## Our Goals

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

## 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!





Photo courtesy of BSF - 2011

Please make a donation today to help us continue saving lives through education, advances in treatment, and finding a cure for Barth syndrome.



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



Member of the National Health Council. BSF abides by all 42 of NHC's best practices.



Member of the Genetic Alliance.



Member of the Guide Star Exchange Program.

#### HEADQUARTERS

Barth Syndrome Foundation  
PO Box 618 / Larchmont, NY 10538 / Phone: 850-273-6974 / E-Mail: [bsfinfo@barthsyndrome.org](mailto:bsfinfo@barthsyndrome.org)

#### PLEASE SEND DONATIONS TO:

Barth Syndrome Foundation / PO Box 582 / Gretna, NE 68028