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

2011 Annual Report

www.barthsyndrome.org

Photos courtesy of BSF
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.
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.

Stephen B. McCandless
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).

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.

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
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.

**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

“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
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
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.
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

<table>
<thead>
<tr>
<th>Awardee</th>
<th>University/Institution</th>
<th>Award Description</th>
<th>Award Period</th>
<th>Funding Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steven M. Claypool, PhD, Johns Hopkins University</td>
<td>Characterizing endogenous mammalian TAZ1</td>
<td>Award — US $40,000 over 1-year period</td>
<td></td>
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</tr>
<tr>
<td>William T. Pu, MD, Children’s Hospital of Boston, Boston, MA, USA</td>
<td>Using induced pluripotent stem cells and modified RNAs to model and correct BTHS</td>
<td>Award — US $40,000 over 1-year period</td>
<td></td>
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</tr>
<tr>
<td>Mindong Ren, PhD, New York University School of Medicine, New York, NY, USA</td>
<td>Drug repositioning for BTHS</td>
<td>Award — US $40,000 over 1-year period</td>
<td></td>
<td></td>
</tr>
<tr>
<td>William T. Pu, MD, Children’s Hospital of Boston, Boston, MA, USA</td>
<td>Using induced pluripotent stem cells and modified RNAs to model and correct BTHS</td>
<td>Award — US $40,000 over 1-year period</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yana Sandlers, PhD, Kennedy Krieger Institute, Baltimore, MD, USA</td>
<td>Characterization of biochemical abnormalities in BTHS patients and mouse model of BTHS</td>
<td>Award — US $21,065 over 1-year period</td>
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<tr>
<td>Ji Zhang, MD, PhD, University of California at San Diego, San Diego, CA, USA</td>
<td>Functional characterization of a mitochondrial lipid phosphatase that involves cardiolipin biosynthesis</td>
<td>Award — US $40,000 over 2-year period</td>
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</tr>
<tr>
<td>Miriam Greenberg, PhD, Wayne State University, Detroit, MI, USA</td>
<td>Cardiolipin deficiency leads to defects in the TCA cycle</td>
<td>Award — US $40,000 over 1-year period</td>
<td></td>
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<tr>
<td>Junhwan Kim, PhD, Case Western Research University, Cleveland, OH, USA</td>
<td>Causative and correlative role of cardiolipin on integrated mitochondrial function in BTHS</td>
<td>Award — US $40,000 over 1-year period</td>
<td></td>
<td></td>
</tr>
<tr>
<td>W. Todd Cade, PT, PhD, Washington University School of Medicine, St. Louis, MO, USA</td>
<td>Effects of resistance training on cardiac, metabolic, and muscle function and quality of life in BTHS</td>
<td>Award — US $39,937 over 1-year period</td>
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</tr>
</tbody>
</table>

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

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

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**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!
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.

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### Statement of Financial Position
December 31, 2011 (with Comparative Totals for December 31, 2010)

<table>
<thead>
<tr>
<th>ASSETS</th>
<th>12/31/2011</th>
<th>12/31/2010</th>
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</thead>
<tbody>
<tr>
<td>Assets:</td>
<td></td>
<td></td>
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<tr>
<td>Cash and cash equivalents</td>
<td>$329,443</td>
<td>$538,826</td>
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<tr>
<td>Investments</td>
<td>1,499,571</td>
<td>1,401,337</td>
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<tr>
<td>Accounts receivable</td>
<td>163,351</td>
<td>89,369</td>
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<td>Prepaid expenses</td>
<td>2,148</td>
<td>2,969</td>
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<tr>
<td><strong>Total assets</strong></td>
<td><strong>1,994,513</strong></td>
<td><strong>2,032,501</strong></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>LIABILITIES AND NET ASSETS</th>
<th>12/31/2011</th>
<th>12/31/2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liabilities:</td>
<td></td>
<td></td>
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<tr>
<td>Accounts payable and accrued expenses</td>
<td>19,302</td>
<td>23,062</td>
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<tr>
<td>Grants payable</td>
<td>80,000</td>
<td>76,980</td>
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<tr>
<td><strong>Total liabilities</strong></td>
<td><strong>99,302</strong></td>
<td><strong>100,042</strong></td>
</tr>
</tbody>
</table>

| 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*
Statement of Activities
For the Year Ended December 31, 2011 (with Comparative Totals for the Year Ended December 31, 2010)

<table>
<thead>
<tr>
<th>Public Support and Other Revenues:</th>
<th>Year Ended 12/31/2011</th>
<th>Year Ended 12/31/2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public Support:</td>
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<tr>
<td>Contributions</td>
<td>$ 706,090</td>
<td>$ 729,756</td>
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<tr>
<td>Investment Income</td>
<td>11,094</td>
<td>26,121</td>
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<tr>
<td>Unrealized Gain (Loss) on Investments</td>
<td>( 1,766)</td>
<td>( 746)</td>
</tr>
<tr>
<td>Total Public Support and Other Revenues</td>
<td>715,418</td>
<td>755,131</td>
</tr>
</tbody>
</table>

| 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 BSF| ( 38,350)            | ( 40,000)              |
| Science & Medicine                 | 164,629                | 156,334                |
| Total Program Expenses              | 634,873                | 862,379                |

| Supporting Services:               |                        |                        |
| Management & General               | 106,966                | 131,225                |
| Development & Fundraising          | 10,827                 | 33,388                 |
| Total Supporting Services          | 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            |

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

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stephen McCurdy, Chairman</td>
<td>Michaela Damin, Board Member</td>
</tr>
<tr>
<td>Lindsay Groff, ex-officio, Executive Director</td>
<td>Stephen Kugelmann, Board Member</td>
</tr>
<tr>
<td>David Axelrod, MD, Board Member</td>
<td>Susan McCormack, Board Member</td>
</tr>
<tr>
<td>Randy Buddemeyer, Treasurer</td>
<td>Katherine McCurdy, Board Member</td>
</tr>
</tbody>
</table>

BARTH SYNDROME FOUNDATION EXECUTIVE STAFF

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lindsay Groff</td>
<td>Executive Director</td>
</tr>
<tr>
<td>Shelley Bowen</td>
<td>Director Family Services &amp; Awareness</td>
</tr>
<tr>
<td>Matthew Toth, PhD</td>
<td>Science Director</td>
</tr>
<tr>
<td>Lynda Sedefian</td>
<td>Executive Assistant</td>
</tr>
</tbody>
</table>

INTERNATIONAL AFFILIATES

Barth Syndrome Trust (UK & Europe)
Michaela Damin, Chair
1 The Vikings
Romsey, Hampshire S051 5RG
United Kingdom

Barth Trust of South Africa
Jeannette Thorpe, Chair
49 Abelia Road
Kloof, Pinetown
3610 Natal
South Africa

Barth Syndrome Foundation of Canada
Lynn Elwood, President
1550 Kingston Road, Suite 1429
Pickering, ON L1V 6W9
Canada

Association Barth France
Florence Mannes, Chair
12, rue Lalo
75116 Paris
France

SCIENTIFIC & MEDICAL ADVISORY BOARD

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michael Schlame, MD – Chairman</td>
<td>Cell Biology &amp; Anesthesiology, NYU School of Medicine, New York, NY, USA</td>
</tr>
<tr>
<td>Peter G. Barth, MD, PhD – Emeritus</td>
<td>Pediatric Neurology (retired), Emma Children’s Hospital / AMC, Amsterdam, The Netherlands</td>
</tr>
<tr>
<td>Barry J. Byrne, MD, PhD</td>
<td>Pediatric Cardiology, Shands Children’s Hospital, University of Florida, Gainesville, FL, usa</td>
</tr>
<tr>
<td>Gerald F. Cox, MD, PhD</td>
<td>Clinical Genetics, Children’s Hospital Boston, Boston, MA; Clinical Research, Genzyme Corp., Cambridge, MA, USA</td>
</tr>
<tr>
<td>Iris L. Gonzalez, PhD</td>
<td>Molecular Diagnostics Lab (retired), A. I. DuPont Hospital for Children, Wilmington, DE, USA</td>
</tr>
<tr>
<td>Miriam L. Greenberg, PhD</td>
<td>Biological Sciences, Wayne State University, Detroit, MI, USA</td>
</tr>
<tr>
<td>Grant M. Hatch, PhD</td>
<td>Lipid Lipoprotein Research, University of Manitoba, Winnipeg, Canada</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Richard I. Kelley, MD, PhD</td>
<td>Division of Metabolism, Kennedy Krieger Institute, Johns Hopkins University, Baltimore, MD, USA</td>
</tr>
<tr>
<td>Colin G. Steward, PhD, FRCP, FRCPCH</td>
<td>Pediatric Hematology, Royal Hospital for Children, Bristol, England</td>
</tr>
<tr>
<td>Jeffrey A. Towbin, MD</td>
<td>Pediatric Cardiology, Cincinnati Children’s Hospital, Cincinnati, OH, USA</td>
</tr>
<tr>
<td>Ronald J. A. Wanders, PhD</td>
<td>Genetic Metabolic Diseases, Academic Medical Center, Amsterdam, The Netherlands</td>
</tr>
<tr>
<td>Katherine R. McCurdy – ex officio</td>
<td>BSF Board Member</td>
</tr>
<tr>
<td>Matthew J. Toth, PhD – ex officio</td>
<td>BSF Science Director</td>
</tr>
</tbody>
</table>
2011 DONORS

SCIENCE & MEDICINE FUND
General Contributions ($50 - $999)
- Barrett, James & Nancy
- Campbell, Tonja
- Galtbreth, Randy & Betty
- Harrigan, Timothy & Lori
- 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
- Bly, 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
- Arquiet, Kevin
- Bardad, 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
- Keams, Richard & Kathleen
- M.C. Dean, Inc.
- Makkin, Louis 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, Nathan & Beth Roberts
- Winstone, Laura

GENERAL FUND
General Contributions ($50 - $999)
- Abbonnito, Leila
- Adelson, Robin
- Alcubes, Elisa
- Alderman, Thomas & Lisa
- Allan, Julia
- Ameriprise Employee Gift Matching
- Ames, Kathleen
- Andrews Trust
- Aurely, Philip
- Axelrod, Dr. David & Jessica
- Azer-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 & Trianne Berger
- Family Charitable Gifts
- Berland, Jonathan & Leslie
- Berry, Rick & Carla
- Berton, David
- Blake One Inc.
- Bodary, Michael & Lisa
- Bogage, Judith
- Bogert, Amy
- Bogert, Carroll
- Bogert, Nicholas & Sally
- Boland, William & Lisa
- Bond, Louis & Kimberly
- Bormatein, 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
- Burts, Cleo
- Butler, David & Cherish
- Calabrese, Frederick & Anne
- Calabrese, Joanne
- Canal, Joseph & Annette
- Capone, Anthony
- Cappello, Frances
- Carney, Catherine
- Cavanaugh, Matthew & Alice
- CMH Auxiliary Gift Shop
- Chandler, Robert & Darla
- Chapin, Stephen & Debbie
- Charenoff, Susan
- Charles Cole Memorial Hospital
- Chemski, 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

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

GENERAL FUND
Stars ($5,000+)
- American Express Gift Matching
- Bly, 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
- Arquiet, Kevin
- Bardad, 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
- Keams, Richard & Kathleen
- M.C. Dean, Inc.
- Makkin, Louis Rice Malkin Fund
- Malkin, Rebecca Swift Malkin Fund
- Mann, Allen & Rosa
- Matelich, George & Susan
- McCormack, Susan
- McCurdy, Chris & Kris
- McCurdy, William & Virginia
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- Minor, Walter & Eleanor
- Osnos, Susan & Peter
- Randolph, Dr. Peter & Helen
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- 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
- Burts, Cleo
- Butler, David & Cherish
- Calabrese, Frederick & Anne
- Calabrese, Joanne
- Canal, Joseph & Annette
- Capone, Anthony
- Cappello, Frances
- Carney, Catherine
- Cavanaugh, Matthew & Alice
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- Chapin, Stephen & Debbie
- Charenoff, Susan
- Charles Cole Memorial Hospital
- Chemski, 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, John & Kerri
- Cricchio, James & Marilyn
- Crowley, Chuck & Diane
- Curniffe, 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
- DuHarrel, Constance
- Duran, Lisa
- Duska, Francesco
- Edelman, Jay
- Elko, Charlotte
- Elliott, Christine
- Epstein, Paul & Leah
- Excella Health Lathrobe 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
- Girskey, Laurie
- Goldstein, Michael
- Goodman, Carol
- Goodwin, William & Virginia
- Gorman, James
- Gottlieber, Karen
- Gottsagen, Alison
- Graham, Megan
- Gray, Donald & Virginia
- Greene, Jeremy
- Greene, Rev. Dorothy
- Grossman, Dr. Harvey
- Guinart, Umut
- Guyer, Doug & Jann
- Hagan, John & Christine
- Halloran, John
- Hamill, Charles & Jo
We appreciate your support and generosity.
TIME & ADVICE

"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 them, 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!
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: bsinfo@barthsyndrome.org

PLEASE SEND DONATIONS TO:
Barth Syndrome Foundation / PO Box 582 / Gretna, NE 68028