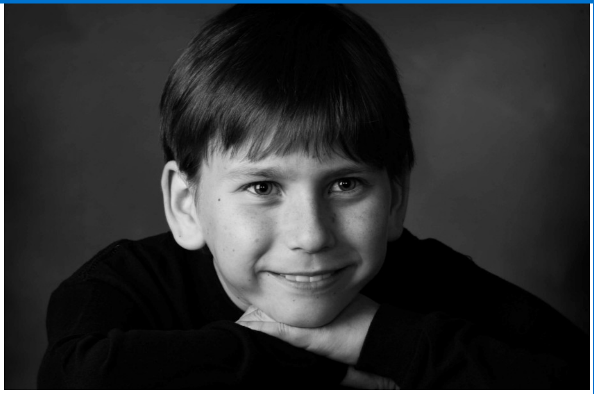
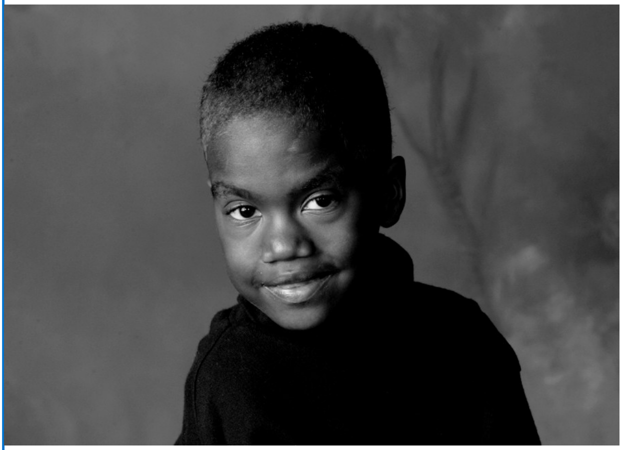
Barth Syndrome Foundation





Barth Syndrome Foundation

www.barthsyndrome.org

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

2008 Annual Report

2008 Barth Syndrome Foundation Annual Report

The Barth Syndrome Foundation (BSF) community certainly had its share of unsettling news in 2008, led by the loss of two sons, and a major benefactor. One's sense of personal loss could be easily mirrored and magnified by the daily paper and the nightly TV news stories of savings and jobs lost, and of instability in institutions we thought were solid and reliable.

It could be overwhelming… but we clearly share a common vision of a world without Barth syndrome (BTHS), and we will not give up this quest until it has been achieved. We all understand that our future will be difficult and that there will continue to be losses… unrecoverable losses. But we are collectively committed to our path because we know that it is the only one we can take. We know that our actions will make a meaningful difference. They already have.

Every year, we take a few more steps in the direction of our goals and vision. 2008 was another such year.

⇒ In January, we welcomed a new Board member, Randy Buddemeyer. Randy brings his business acumen and serves as BSF's Treasurer.

⇒ In February, we awarded nine new research grants for over $333,000. In addition, three scientists associated with BSF have recently been awarded major NIH research grants, based in part on work that has been funded or encouraged by BSF.

⇒ In July, BSF hired its first Executive Director, Linda Stundis.

⇒ Also in July, we held our Fourth International Barth Syndrome Scientific, Medical & Family Conference featuring two days of clinics where critically important data were gathered from 29 affected boys and young men for the Barth Syndrome Registry and BioRepository, followed by dual tracks of presentations and symposia for and among scientists/clinicians and families. These meetings are critically important to the advancement of collaboration, science and medicine, and understanding among all three key groups.

⇒ At year end, through Linda Stundis' efforts, BSF became fully accredited by the Better Business Bureau, adding their endorsement to that of the National Health Council.

⇒ By contracting with Taconic Artemis, and through their work over much of 2008, we have succeeded in reaching a major milestone toward the creation of a BTHS mouse—a critically important animal model that we hope will help us better understand Barth syndrome and lead us to a cure.

Our progress and accomplishments over the past year have been the result of extraordinary commitment across the BSF community—our families, in their compassionate support of one another as well as their tireless fundraising efforts to support our programs and mission; our physicians and scientists who are successfully challenging the limitations of BTHS science and medicine to date; and of course our donors, whose funding has leveraged the passion of our families and the dedication of our researchers, and in so doing, brought us closer to our vision of *a world in which Barth syndrome will no longer cause suffering or loss of life.* We thank you.

Stephen B McCurdy

Stephen B. McCurdy
Chairman of the Board
Barth Syndrome Foundation

Linda Stundis
Executive Director
Barth Syndrome Foundation

All non-collage photos courtesy of Amanda Clark. All photos 2006-2008.

Major Advances in both Barth Syndrome Foundation and Barth Syndrome Science to Date

BSF provided nearly $1.5M in research grant funding as of 2009

4th Intl. Barth Syndrome Conference and SMAB Meeting—2008

Executive Director hired—2008

1st SMAB retreat—2007

President hired—2007

Executive Assistant hired—2007

3rd Intl. Barth Syndrome Conference and SMAB Meeting—2006

Science Director hired—2006

BSF provided $.5M in research grant funding as of 2006

BRR Medical Advisory Board created—2005

Barth Medical Database & BioRepository (BRR) created—2005

2nd Intl. Barth Syndrome Conference and SMAB Meeting—2004

1st Intl. Barth Syndrome Conference and SMAB Meeting—2002

Scientific and Medical Advisory Board (SMAB) + BSF Research Grant Program begun—2002

Newsletter + Listserv created—2001/2002

BSF, Inc. established—2000/2001

1st informal Barth gathering—2000

Development of a human tafazzin monoclonal antibody created at NIH at BSF's request—2009

***TAZ* knockdown mouse created thru BSF contract—2009**

Development of bloodspot screening for BTHS funded by BSF grant—2008

Fruit fly/zebra fish BTHS models created with support of BSF funding—2006

Yeast BTHS model created with support of BSF funding—2004

Advances made in clinical description and understanding of BTHS

Fuller understanding of *TAZ* gene developed

Tafazzin found to be involved in cardiolipin remodeling—2000

***TAZ* gene discovered—1996**

In all of the years that I have worked with disease advocacy groups, I have never seen one that compares to this. I find myself surrounded by people who are working together to make a difference. There is no ego and there is no bitterness. The overwhelming commitment of teamwork and optimism is the evident tone throughout this community. ~ Peter G. Barth, MD, PhD, Emeritus, Pediatric Neurology (retired), Emma Children's Hospital/AMC, Amsterdam, The Netherlands

Our Mission

Today, Barth syndrome (BTHS) 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."

What is Barth syndrome (BTHS)?

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

Though not always present, cardinal characteristics of this multi-system disorder often include combinations and varying degrees of:

⇒ **Cardiomyopathy** (dilated or hypertrophic, possibly with left ventricular noncompaction and/or endocardial fibroelastosis)

⇒ **Neutropenia** (chronic, cyclic, or intermittent)

⇒ **Underdeveloped skeletal musculature and muscle weakness**

⇒ **Growth delay** (abnormal growth pattern, similar to but more severe than constitutional growth delay)

⇒ **Exercise intolerance**

⇒ **Cardiolipin abnormalities**

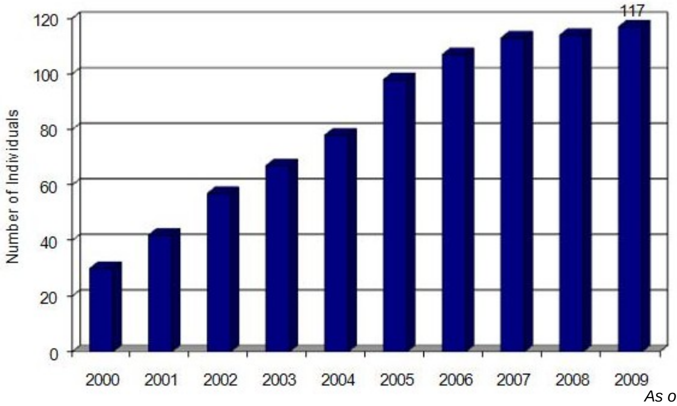
⇒ **3-methylglutaconic aciduria**

Family Services 2008 *(Valerie "Shelley" Bowen, President)*

The Barth Syndrome Foundation (BSF) Family Services provides a caring community that offers each Barth family information, guidance and emotional support. We are dedicated to education, advancing treatments and finding a cure for Barth syndrome (BTHS). Families can find numerous resources regarding BTHS and the issues families deal with on our website (www.barthsyndrome.org). In addition, on behalf of BSF families, Shelley Bowen, BSF President, provided testimony at the Social Security Administration's *Compassionate Allowance Outreach Hearing on Rare Diseases* in December 2007. As a result of her testimony, Barth syndrome is being considered for "fast-track" social security benefits.

The latest census shows that BSF has grown to a total of 117 boys/young men living around the world, with 26 more awaiting a confirmed diagnosis. When new families reach out to BSF, we are there for them and in due course, they are introduced to the listserv—our global lifeline on the internet and the place where no question is too small, answers come quickly, and everyone understands.

BTHS Numbers are Growing ~ Number of Living Affected Individuals in BSF Family Registry



As of June 30, 2009

Figure 1. In 2008, BSF gained five newly diagnosed individuals in the Family Registry, but lost two boys, ages 6 and 10.

Physician Awareness 2008

(Valerie "Shelley" Bowen, President and Stephen Kugelmann, Board Member)

During 2008, BSF representatives attended eight specialty-related medical and/or scientific conferences to raise physician awareness, furthered relationships with the National Institutes of Health (NIH) and learned more about their programs, cultivated scientists, and networked with other family/medical/ scientific organizations.

- ⇒ Cardiology 2008: 11th Annual Update on Pediatric Cardiovascular Disease (CHOP meeting); February 6-10, 2008, Scottsdale, AZ
- ⇒ American College of Medical Genetics; March 13-16, 2008, Phoenix, AZ
- ⇒ Mitochondrial Summit Meeting: Hosted by the Muscular Dystrophy Association and the Friedreich's Ataxia Research Alliance; May 20-21, 2008, Phoenix, AZ
- ⇒ Planning for the Future: An NINDS Forum; May 16, 2008, Bethesda, MD
- ⇒ NHLBI 9th Annual Public Interest Organization Meeting; June 9-10, 2008, Bethesda, MD
- ⇒ Society for Heart and Vascular Metabolism: 6th Annual Conference; June 29-July 1, 2008, Boston, MA
- ⇒ Mitochondrial Biology in Cardiovascular Health & Diseases Conference; October 6-7, 2008, Bethesda, MD
- ⇒ American Society of Human Genetics: 58th Annual Meeting; November 11-15, 2008, Philadelphia, PA

National Institutes of Health Committee Appointments 2008

CETT: Collaboration, Education and Test Translation Program developed by the NIH Office of Rare Diseases Research in collaboration with the Centers for Disease Control and Prevention

CETT Review Board Member: Kate McCurdy, BSF Board Member

<u>CETT Goals (as stated in their website www.cettprogram.org):</u>

- ⇒ Promote new test development for rare genetic diseases.
- ⇒ Facilitate the translation of genetic tests from research laboratories to clinical practice.
- ⇒ Establish collaborations and provide education about rare genetic diseases, related genetic research and clinical impact of testing.
- ⇒ Support the collection and storage of genetic test result information in publicly accessible databases to leverage the information into new research and treatment possibilities.

International Scientific, Medical & Family Conference 2008

In 2008, the 4th biennial Barth Syndrome International Scientific, Medical & Family Conference was held in Clearwater Florida, July 21—26. Two hundred and thirty Barth syndrome families, physicians, scientists, and volunteers from around the globe were in attendance. There is no BSF program that has a greater impact on our mission. Scientists were inspired not only by cutting-edge science presented by researchers from around the globe, but also by witnessing the remarkable spirit of our families and by meeting the boys who benefit from their research. Physicians were able to see and hear about a number of affected individuals, thus helping improve treatment approaches to the disorder. Families were empowered as advocates, as their perspectives were not only heard but taken to heart. Relationships were forged and research collaborations were born. Ideas flourished. Commitment to the cause deepened. An extraordinary sense of community was strengthened.

Family Sessions

The Family sessions were comprised of a two-day clinic, family educational sessions, and small group sessions for Barth syndrome youth and siblings. The educational and small group sessions focused on affected individual sessions, sibling sessions, and family educational sessions which included topics such as *Risks…Trends…Management* by Richard Kelley MD, PhD, *Cardiac Aspects of Barth Syndrome* by Carolyn Spencer MD, and *Hematological Aspects of Barth Syndrome* by Colin Steward FRCP, FRCPCH, PhD. A report on the 2008 research funded by BSF was also offered. Recreational activities were provided for the children, and evening social events brought the families, physicians, and scientists together in a way unprecedented across the scientific and medical communities.

Barth Syndrome Clinics

Each family was offered individual consultations with Barth syndrome clinicians who provided their time *pro bono*. The expertise offered spanned the spectrum of this multi-system disease. The IRB-approved Cardiology Clinic offered echocardiograms, EKG's, and a stress test; blood draws also provided research data for the Barth Syndrome Medical Database and BioRepository (BRR). In addition, metabolic, hematologic, neurologic, genetic, and muscle strength research data were collected for the BRR.

Scientific & Medical Sessions

The Scientific and Medical sessions of the 2008 International Conference attracted more than 50 scientists and physicians, and featured 23 lectures, 17 posters, and three young men who spoke about their struggles in living with Barth syndrome (BTHS). Topics ranged from the understanding of how the cardiolipin molecule functions to how the metabolism of BTHS individuals is altered. New data and unpublished reports were shared which reinforced the conviction that this was a special meeting marked by openness and a free exchange of ideas among all of the participants.

(Cont'd on page 8)

(Cont'd from page 7)

Among the many new ideas and observations, one area of special importance was the results of the fruit fly model of BTHS. Drs. Mindong Ren and Michael Schlame showed that many of the effects of a tafazzin deletion in the fruit fly were reversed by a second mutation in the gene for calcium-independent phospholipase A2. This phospholipase gene is involved with lipid metabolism which includes cardiolipin. More importantly, these researchers showed that a chemical compound that inhibits the protein product of this phospholipase also reversed some of the biochemistry abnormalities associated with the tafazzin mutation in BTHS lymphoblasts. This result is significant because it shows how a chemical compound ultimately might be useful as pharmacological treatment for Barth patients.

Following the Conference, the BSF Scientific and Medical Advisory Board (SMAB) met to discuss several items of importance, including the tafazzin knockdown mouse, the importance of the citric acid cycle to the pathology of BTHS, and the need to obtain monoclonal antibodies against human tafazzin.

Web-Ex

In a first among rare disease organizations, BSF partnered with WebEx to broadcast the Family as well as Scientific and Medical sessions over the internet for families, physicians, and scientists around the world who could not attend the Conference.

BSF Conference Testimonials

To gain support from other parents and families, receive hope by seeing and hearing the affected individuals, and increase knowledge about Barth syndrome from doctors and medical teams, is critical for everyone involved with this condition. By attending the 2008 BSF Conference, we achieved and exceeded each of these goals! ~ Tracy Brody, BTHS Family, Iowa, USA

...This was my second opportunity to attend an international Barth syndrome meeting, and once again I was impressed by the breadth and depth of the presentations. ...Connections were made or strengthened, and these may assist us in the future to better diagnose and care for patients with Barth syndrome. ~ Rik De Decker, MSc, MB ChB, FCPaed (SA), Cert Med Genetics (SA), DCH (Lond), Senior Specialist and Paediatric Cardiologist, Red Cross Children's Hospital, Cape Town, South Africa

The quality and broad spectrum of scientific presentations...was very impressive and truly extraordinary. Participation of many outstanding and enthusiastic scientists ...provided a unique opportunity to closely discuss most recent findings and to plan new, more comprehensive collaborative studies aimed at understanding the pathophysiology of Barth syndrome. ~ Andrew Aprikyan, PhD, Division of Hematology, University of Washington School of Medicine, Seattle, WA, USA

Science and Medicine 2008 (*Matthew J. Toth, PhD, Science Director)*

Research Grant Program

BSF awarded nine new research grants for over $333,000 in early 2008 (2007 grant cycle) and another four grants exceeding $143,000 in early 2009 (2008 grant cycle). The following is a summary of the main focus of each grant awarded in the 2008 cycle. The breadth of these awards clearly demonstrates the progress being made and increased exposure of Barth syndrome (BTHS) research within the scientific and medical communities. These 2008 grant recipients are testing ideas or measuring parameters that will lead to a better understanding and perhaps a better treatment of BTHS individuals. All of the recipients are building on previous work performed in their laboratory or at the clinics of the BSF biennial conferences.

Miriam Greenberg, PhD, Professor and Associate Dean, Wayne State University, Detroit, MI
“The role of tafazzin in mitochondrial protein import—implications for Barth syndrome”
USD $40,000 for 1 year

Using yeast as a model system, Dr. Greenberg is expanding on her recent discovery of the synthetic lethality of tafazzin and Tom5 mutations. This discovery shows that there is a connection between the causative gene of BTHS, tafazzin, and at least one member of the mitochondrial protein import machinery, Tom5 (translocase of the outer membrane 5). This connection is made even more interesting by considering that the autosomal recessive disease called DCMA (dilated cardiomyopathy and ataxia) or Barth-like syndrome is caused by a mutation in the DnaJC19/TIM14 gene which is a member of the mitochondrial protein transport mechanism. The common symptoms between BTHS and DCMA (cardiomyopathy, neutropenia, 3-methyglutaconic aciduria, and growth delay) suggest a common biochemical mechanism. By understanding what aspects of the biochemical dysfunction caused by a tafazzin mutation cause what symptoms, one may be able to logically identify potential treatments. For example, can simply adding certain fatty acids to the diet be useful?

W. Todd Cade, PT, PhD, Assistant Professor, Washington University School of Medicine, St. Louis, MO
“Characterization of nutrient metabolism in Barth syndrome”
USD $39,996 for 1 year

This clinical project is designed to determine how the metabolism of BTHS individuals differs from their unaffected siblings. Specifically, Dr. Cade will measure the whole-body glucose, fatty acid, and protein/ amino acid metabolism during fasting or the post-absorptive state by feeding five BTHS individuals and five unaffected individuals a special diet over two days. During these two days various measurements will be taken that can identify how their bodies process their food using: breath sample collection, magnetic resonance imaging of the heart, echocardiography, blood parameter analysis, dual-energy x-ray absorptiometry (DEXA), and intravenous infusion (insulin-glucose clamp test) with blood sampling. By determining if and how differently the BTHS individuals process food, we should better understand how their symptoms relate to their known biochemical dysfunction. This knowledge should be able to impact ideas about a treatment and is a logical outgrowth from the data collected at the clinical sessions of the BSF International Conferences over the years.

Genevieve Sparagna, PhD, Faculty Research Associate, University of Colorado, Boulder, CO
"Fatty acid combinational therapy for Barth syndrome investigated using a rat model of heart failure"
USD $40,000 for 2 years

In this proposal, Dr. Sparagna is pursuing her recent discovery that a diet supplemented with high linoleic safflower oil can increase survival and increase heart tetralinoleoyl cardiolipin levels in rats. Dr. Sparagna believes that the expected benefits of linoleoyl supplementation may have been attenuated or reversed in humans by a biochemical perturbation that increased the production of an inflammation-associated fatty acid—arachidonic acid. Dr. Sparagna will investigate whether sucrose in the diet of SHHF rats increases inflammation and whether linoleoyl acid supplementation can ameliorate this. She postulates that the presence of refined sugar in the diet (not in typical rat diets but certainly present in the human diet) makes a difference with regard to the cardiolipin and cardiac parameters. Dr. Sparagna will test whether adding fish oils to the linoleoyl diet can improve the cardiolipin and cardiac parameters, with (or without) refined sugars. She hypothesizes that by using fish oil to inhibit some of the enzymes that may lead to inflammation (inhibition of the delta 6 and the delta 5 desaturases of fatty acid elongation), a better cardiac outcome may be attainable in the SHHF rat. Obviously, the same treatment would be amenable to trial in humans.

Ashim Malhotra, PhD, Postdoctoral Fellow, New York University School of Medicine, New York, NY
"Distribution of tafazzin and cardiolipin in mitochondrial protein complex assemblies"
USD $23,980 for 1 year

Using the fruit fly model system, Dr. Malhotra will analyze the tafazzin deletion strain and other strains for the assembly of respiratory supercomplexes. The derangement of respiratory protein supercomplexes in BTHS cell cultures has been published as a distinguishing characteristic of this human mitochondrial disease. Dr. Malhotra's preliminary work shows that supercomplexes are altered in some of these fruit fly mutants. Dr. Malhotra hopes to better understand how cardiolipin dysfunction can result in membrane changes and supercomplex formation which has not been studied in detail with an animal model before.

During the seventh year of the BSF Research Grant Program, the number of publications about Barth syndrome (BTHS) continued to increase (Figure 2). Many of these publications can be associated with the grant funding and with the conferences that the BSF has sustained over the years.

(Continued on page 11)

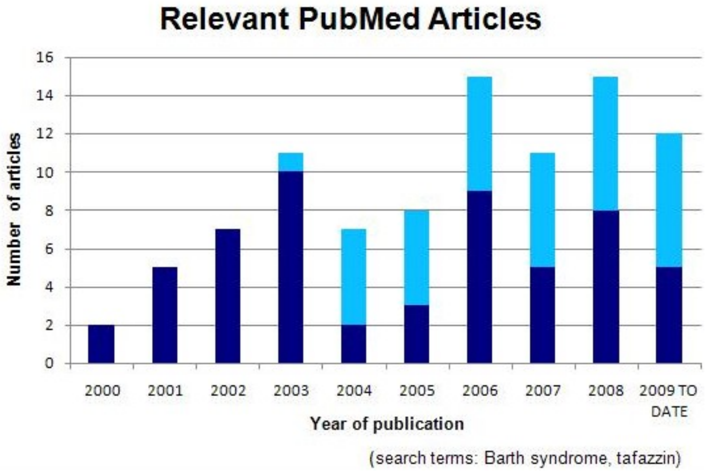


Figure 2. Publications listed in PubMed concerned with BTHS or the tafazzin gene tallied by year of publication. Light blue portions of the bars correspond to publications that acknowledge support from the BSF Research Grant Program which began in 2002. Note that there were only 11 relevant publications in total before 2000.

BSF Strategy of Funding Research ‘Seed’ Grants is Working

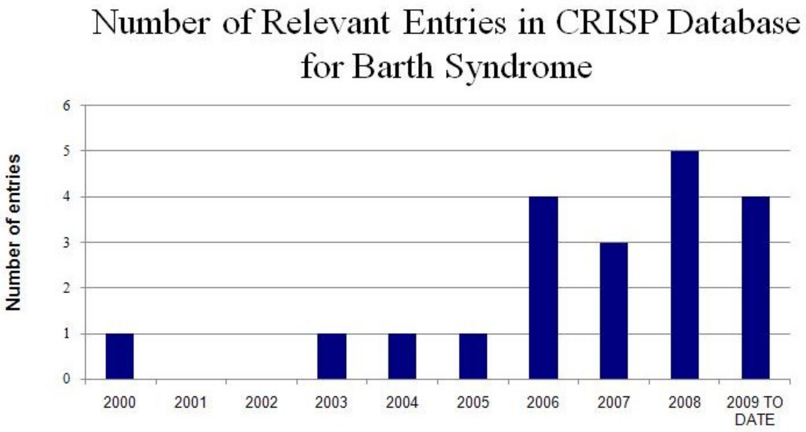

Number of Relevant Entries in CRISP Database for Barth Syndrome

Figure 3: BSF was established in 2000, and the BSF grant program began in 2002. Computer Retrieval of Information on Scientific Projects (CRISP) is a searchable database of federally funded biomedical research projects conducted at universities, hospitals, and other research institutions.

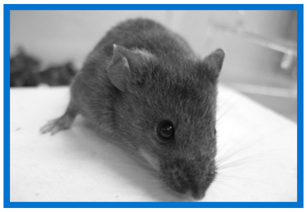
Barth Syndrome Researchers and National Institutes of Health Funding

During this past year, several Barth syndrome (BTHS) researchers have received National Institutes of Health (NIH) grants to continue their studies on BTHS. These awards are for several years each and the funds made available are usually in the range of several hundred thousand dollars. Dr. Mindong Ren recently received an R01 award (start April, 2009) for *“Barth syndrome: A model for investigation the role of cardiolipin in mitochondria.”* Dr. Miriam Greenberg received an R21 award (start April, 2008) for *“Synthetic lethal interactions in Barth syndrome.”* Dr. Steven Claypool, who spoke at the 208 International Conference, received an R00 award (start September, 2008) for *“Characterizing tafazzin and Barth syndrome mutant tafazzins.”* Drs. Greenberg and Ren are previous or current BSF Research Grant recipients.

Monoclonal Antibody Production Against Human Tafazzin

One important tool that the BTHS research community lacks is an antibody that recognizes human tafazzin protein in primary cell lysates. In 2007, with the help of Dr. Michael Schlame, the BSF subsidized an attempt to make polyclonal antibodies against human tafazzin, but it was not satisfactory. On October 31, 2008, the National Institutes of Health (NIH) requested suggestions for protein targets to make monoclonal antibodies under the sponsorship of the Office of Rare Disease Research and the National Institute of Neurological Disorders and Stroke. Monoclonal antibodies are frequently superior to polyclonal antibodies, but they are more expensive to produce. The BSF and its research colleagues proposed human tafazzin as a protein target, which was accepted. Drs. Stephen Claypool and Michael Schlame have volunteered to help with the validation of these monoclonal antibodies with the eventual goal of distributing them to any qualified researcher.

The Mouse Model in Barth Syndrome Research



Some of the most important tools in finding new treatments for human disease are animal models of that human disease. Barth syndrome (BTHS) research already has benefited tremendously from the creation of models of the disorder in yeast (*Saccharomyces cerevisiae*), fruit flies (*Drosophila melanogaster*) and zebrafish (*Danio rerio*), but the creation of a mammalian model has proven to be extremely difficult. With 2008 funding from BSF, a German company called Taconic Artemis recently has succeeded in reaching a major milestone toward the creation of a BTHS mouse—a critically important animal model that we hope will help us better understand BTHS and lead us to a cure.

Several expert attempts utilizing various approaches to make a mouse model of BTHS have not been successful. These attempts involved trying to create a mouse in which the function of the gene that causes BTHS, called tafazzin, is completely "knocked out." From the beginning of the BSF Research Grant Program, the creation of such a "Barth syndrome mouse" has been a high priority and has received specific donor support from the Annenberg Foundation and from the Paula and Woody Varner Fund.

Because previous approaches did not seem to be working, the BSF in April 2008, commissioned the TaconicArtemis to make a different sort of mouse model of BTHS—a tafazzin "knockdown" mouse. If successful, these animals would have the function of the relevant gene reduced (knocked down) but not completely eliminated (knocked out). This approach has great potential. These tafazzin "knockdown" mice have been delivered to the Khuchua/Strauss laboratory at Cincinnati Children's Hospital, the Byrne laboratory at the University of Florida, and the Houtkooper/Auwerx laboratory at the EPFL in Lausanne, Switzerland. While researchers will take several months to measure how closely these knockdown mice will mimic the symptoms of human BTHS, we are glad to report the significant progress made in providing this extremely important scientific and drug-discovery research tool.

Barth Syndrome Research in the Scientific News

In the February 2009 issue of the prestigious *Proceedings of the National Academy of Sciences*, *USA*, the laboratories of Mindong Ren and Michael Schlame at the New York University Langone Medical Center published an article which caused an unusual but justified degree of attention (*Proc Natl Acad Sci U S A*. 2009 Feb 17;106(7):2337-41). Dr. Ren is a previous BSF Research Grant recipient, while Dr. Schlame is a member of BSF Scientific and Medical Advisory Board.

This paper describes the great progress made by using the fruit fly model of Barth syndrome (BTHS). As partly revealed at the 2008 BSF International Conference, the researchers used the power of genetics to isolate genes that interact with the causative gene of BTHS, tafazzin. They discovered that mutations in a specific enzyme called calcium-independent phospholipase A2 can fix or suppress the defects of a fly with a total loss of the tafazzin gene. In addition, the authors treated BTHS lymphoblasts with a chemical compound (bromoenol lactone) that inhibits the same phospholipase identified above—a significant achievement which is directly related to drug discovery—and found a reversing of the cardiolipin abnormality. Other suppressor mutations are being isolated with the aim of finding compounds that can act as pharmacological surrogates for these suppressor mutations.

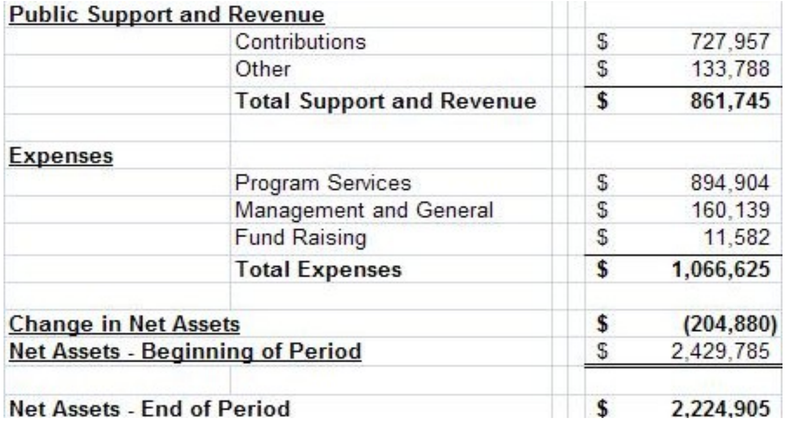
Finances 2008

Although BSF ran a deficit in 2008 (for only the second time in our eight years of existence), our balance sheet remains strong. It should be noted that BSF's conservative investments in bank CDs insured that we experienced no investment losses in 2008, despite the turmoil in the world's financial markets. Our deficit resulted from planned investments in our programs, particularly research, science and medicine, and our biennial Barth Syndrome International Conference, as well as investments in our future, most notably our search for and hiring of Linda Stundis as our new Executive Director. Linda's arrival could not be more timely, as BSF continues to grow in programs and complexity and is already benefiting from her skills, experience and leadership after less than a year.

As we planned the budget for 2009, we knew, like most non-profits, that we faced a serious fund-raising challenge in the current difficult economic climate. We have economized on our programs and administrative budgets everywhere we could without doing long-term damage to our programs or our future. The net assets on our balance sheet (essentially, the funds we have in the bank or in CDs) can sustain us for a while, but additional fund-raising efforts are critical if we are to continue the great progress already made by our programs. We appreciate the steadfast loyalty of our long time donors and hope that they can sustain, even increase, their gifts to BSF. And we will need to continue to search for new donors who can share our vision and help to insure our success. Most of all, we need to ask every member of our community to step up and become not just a contributor, but a fund raiser… an advocate for and proponent of BSF.

Statement of Activities

Dec. 31, 2008



Public Support and Revenue			
	Contributions	$	727,957
	Other	$	133,788
	Total Support and Revenue	**$**	**861,745**
Expenses			
	Program Services	$	894,904
	Management and General	$	160,139
	Fund Raising	$	11,582
	Total Expenses	**$**	**1,066,625**
Change in Net Assets		**$**	**(204,880)**
Net Assets - Beginning of Period		$	2,429,785
Net Assets - End of Period		**$**	**2,224,905**

Statement of Financial Position

Dec. 31, 2008

Assets			
	Current Assets	$	2,375,329
	Other Assets	$	-
	Total Assets	**$**	**2,375,329**
Liabilities		$	150,424
Net Assets			
	Unrestricted	$	1,486,721
	Temporarily Restricted	$	738,184
Total Net Assets		**$**	**2,224,905**
Total Liabilities and Net Assets		**$**	**2,375,329**

BSF Finances

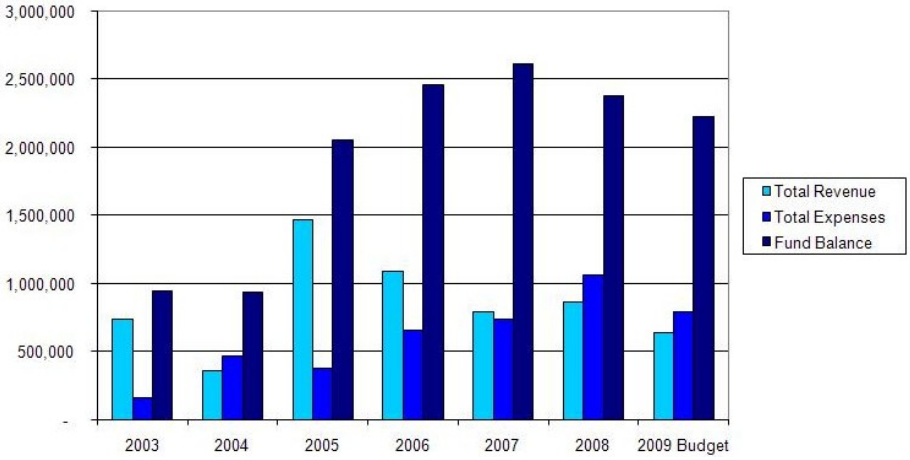


Figure 4. Expenses in Years 2004, 2006, and 2008 reflect the biennial International Conferences. BSF's conservative investments in bank CDs insured that we experienced no investment losses in 2008, despite the turmoil in the world's financial markets.

2008 Donors

PAULA & WOODY VARNER FUND

Stars ($5,000 +)
Dillon Foundation
Yanney, Michael & Dr. Gail

Angels ($1,000 - $4,999)
The New York Community Trust
Voell, Richard
Wilkins, Dr. Mike & Sue

General Contributions ($50 – $999)
Acklie Charitable Foundation
Allman, Peter & Maureen
Allman, Tom
Basler, Dr. Rod
Benyon, Dave & Elizabeth
Brehm, Russell & Louise
Buckley, Les & Nancy
Burmeister, Charles & Marita
Burmeister, Jon & Jackie
Campbell, Robert & Candace
Carveth, Dr. Steve & Beth
Cheatham, Dr. John & Linda
Danziger, Sheldon & Sandra
Deeter, Doug & Leslie
Desmond, Sally
Dittman, Alice
Farrar, Doug & Shawn
Firestone, Dave & Jane
Gelber, Dr. Ben & Elaine
Griffin, Dr. William
Haessler, John & Nancy
Hedgecock, Norm & Debbie
Henricks, Dr. Bruce & Peggy
Hurlbut, Dr. Greg & Sheri
Jensen, Tom & Marilyn
Kaiser, Matt & Bridget
Keating, Barbara & Con
Kenyon, Barbara & Allan
Kiechel, Dr. Fred & Vivian
Lincoln Community Foundation
Linder, Dr. Max & Pat
Massengale, Dr. Martin & Ruth
McBride, John & Jean
Minnick, Gates & Daisy
Norris, Dr. Mike & Mary
Osborne, Dr. Tom & Nancy
Otte, Rob & Carolyn
Raun, Robert & Eileen
Rawley, Ann
Roskens, Ronald & Lois
Roth, Dr. Bob & Marcia
Russell, Brehm
Seacrest, Shawn
Seacrest, David & Susan
Shamblin, Dave & Sue
Shreve, Bill & Linda
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The BSF Scientific and Medical Advisory Board (SMAB) is a world-class group of scientists and physicians with expertise in the diverse fields of research and the multiple systems affected by Barth syndrome (BTHS). These advisors review all research grant proposals and make their recommendations to the BSF Board which retains final grant approval authority. In addition, the SMAB advises on scientific and medical programs, participates in the International Conferences, and the SMAB clinicians offer consultations to our families and their physicians.

The Barth Syndrome Foundation Scientific and Medical Advisory Board		
Richard I. Kelley, MD, PhD *Chairman* Division of Metabolism Kennedy Krieger Institute Johns Hopkins University Baltimore, Maryland	**Iris L. Gonzalez, PhD** Molecular Diagnostics Lab *(retired)* A. I. DuPont Hospital for Children Wilmington, Delaware	**Jeffrey A. Towbin, MD** Pediatric Cardiology Cincinnati Children's Hospital Cincinnati, Ohio
Peter G. Barth, MD, PhD *Emeritus* Pediatric Neurology *(retired)* Emma Children's Hospital/AMC Amsterdam, The Netherlands	**Miriam L. Greenberg, PhD** Biological Sciences Wayne State University Detroit, Michigan	**Ronald J. A. Wanders, PhD** Genetic Metabolic Diseases Academic Medical Center Amsterdam, The Netherlands
Barry J. Byrne, MD, PhD Pediatric Cardiology Shands Children's Hospital University of Florida Gainesville, Florida	**Grant M. Hatch, PhD** Lipid Lipoprotein Research University of Manitoba Winnipeg, Canada	**Katherine R. McCurdy** *ex-officio* Board Member Barth Syndrome Foundation Larchmont, New York
Gerald F. Cox, MD, PhD Clinical Genetics Children's Hospital Boston, Massachusetts Senior Medical Director Clinical Research, Genzyme Corp. Cambridge, Massachusetts	**Michael Schlame, MD** Cell Biology & Anesthesiology NYU School of Medicine New York, New York	**Matthew J. Toth, PhD** *ex-officio* Science Director Barth Syndrome Foundation Iselin, New Jersey
Salvatore DiMauro, MD Neurology Columbia University College of Physicians & Surgeons New York, New York	**Colin G. Steward, FRCP, FRCPCH, PhD** Pediatric Hematology Bristol Royal Hospital for Children Bristol, England	

Barth Syndrome Registry and BioRepository

Through an agreement with the University of Florida and with BSF's sponsorship, the Barth Syndrome Medical Database and BioRepository (BRR) was established to promote the collection and sharing of clinical histories and biological samples (including cell lines) of Barth syndrome (BTHS) patients. While BSF owns all of the data and samples in the Registry, it is available to any qualified researcher, worldwide, who is interested in studying BTHS (http://barthsyndrome.org/english/View.asp?x=1513).

To date, there are 61 individuals enrolled in the database, supplemented by 49 DNA samples, 40 cell lines, and 3 myocardial samples. Cell lines have been distributed to four researchers internationally with one pending.

A new web-based platform was developed in 2008 and includes all self-reported data provided by the families. Abstracting and entering medical record data will begin in 2009.

Barth Syndrome Registry and BioRepository Advisory Board	
Carolyn Spencer, MD Co-Principal Investigator Department of Cardiology Children's Hospital Boston, Massachusetts	**Barry J. Byrne, MD, PhD** Co-Principal Investigator Pediatric Cardiology Shands Children's Hospital University of Florida Gainesville, Florida
Gerald Cox, MD, PhD Clinical Genetics Children's Hospital Boston, Massachusetts Senior Medical Director Genzyme Corporation Cambridge, Massachusetts	**Matthew J. Toth, PhD** Science Director Barth Syndrome Foundation Iselin, New Jersey
Richard I. Kelley, MD, PhD Division of Metabolism Kennedy Krieger Institute Johns Hopkins University Baltimore, Maryland	**Melissa Maisenbacher, MS, CGC,** *ex-officio* Medical Data Abstraction University of Florida College of Medicine Gainesville, Florida
Michael Schlame, MD Department of Anesthesiology New York University School of Medicine New York, New York	**Linda Stundis,** *ex-officio* Executive Director Barth Syndrome Foundation Chestnut Hill, Massachusetts
Colin G. Steward, FRCP, FRCPCH, PhD Pediatric Hematology Bristol Royal Hospital for Children Bristol, England	

Barth Syndrome Foundation, Inc. (BSF) and International Affiliates

Barth Syndrome Foundation, Inc.

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BSF International Affiliates

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Website: www.barthsyndrome.org/South_Africa.html

Note: Complete copies of BSF's Annual Reports, Audited Financial Statements, and Form 990s are available on BSF's website at www.barthsyndrome.org.

SCHALL & ASHENFARB Certified Public Accountants, LLC

IRA L. SCHALL, CPA
DAVID C. ASHENFARB, CPA

THE BARTH SYNDROME FOUNDATION, INC.

Audited Financial Statements

December 31, 2008 and 2007

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SCHALL & ASHENFARB CERTIFIED PUBLIC ACCOUNTANTS, LLC

IRA L. SCHALL, CPA
DAVID C. ASHENFARB, CPA

INDEPENDENT AUDITORS' REPORT

To the Board of Directors of
The Barth Syndrome Foundation, Inc.

We have audited the accompanying statement of financial position of The Barth Syndrome Foundation, Inc. (the "Foundation") as of December 31, 2008 and 2007 and the related statements of activities, functional expenses, and cash flows for the years then ended. These financial statements are the responsibility of the Foundation's management. Our responsibility is to express an opinion on these financial statements based on our audits.

We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audits to obtain reasonable assurance about whether the financial statements are free of material misstatements. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audits provide a reasonable basis for our opinion.

In our opinion, based on our audits, the financial statements referred to above present fairly, in all material respects, the financial position of The Barth Syndrome Foundation, Inc. as of December 31, 2008 and 2007, and the changes in its net assets and its cash flows for the years then ended in conformity with accounting principles generally accepted in the United States of America.

Schall + Ashenfarb

Schall & Ashenfarb
Certified Public Accountants, LLC

March 16, 2009

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THE BARTH SYNDROME FOUNDATION, INC.
STATEMENT OF FINANCIAL POSITION
AT DECEMBER 31, 2008 AND 2007

	12/31/08	12/31/07
Assets		
Cash and cash equivalents (Notes 2g and 2h)	$2,242,382	$2,317,189
Investments (Note 5)	0	286,833
Accounts receivable	7,235	1,477
Unconditional promises to give (Note 2c and 2e)	125,000	973
Prepaid expenses	712	7,297
Total assets	$2,375,329	$2,613,769
Liabilities and Net Assets		
Liabilities:		
Accounts payable and accrued expenses	$15,581	$15,684
Grants payable (Note 4)	134,843	168,300
Total liabilities	150,424	183,984
Net Assets: (Note 2b)		
Unrestricted	1,486,721	1,993,659
Temporarily restricted (Note 3)	738,184	436,126
Total net assets	2,224,905	2,429,785
Total liabilities and net assets	$2,375,329	$2,613,769

The attached notes and auditors' report
are an integral part of these financial statements.

THE BARTH SYNDROME FOUNDATION, INC.
STATEMENT OF ACTIVITIES
FOR THE YEARS ENDED DECEMBER 31, 2008 AND 2007

	12/31/08			12/31/07		
	Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
Public Support and Revenue:						
Contributions (Notes 2c and 3)	$361,165	$366,792	$727,957	$291,849	$382,608	$674,457
Interest income	133,788		133,788	116,505		116,505
Net assets released from restrictions:						
Satisfaction of program restrictions (Note 3)	64,734	(64,734)	0	335,697	(335,697)	0
Total public support and revenue	559,687	302,058	861,745	744,051	46,911	790,962
Expenses:						
Program services	894,904		894,904	596,095		596,095
Management and general	160,139		160,139	81,864		81,864
Fundraising	11,582		11,582	12,372		12,372
Total expenses	1,066,625	0	1,066,625	690,331	0	690,331
Change in net assets	(506,938)	302,058	(204,880)	53,720	46,911	100,631
Net assets - beginning of year	1,993,659	436,126	2,429,785	1,939,939	389,215	2,329,154
Net assets - end of year	$1,486,721	$738,184	$2,224,905	$1,993,659	$436,126	$2,429,785

The attached notes and auditors' report
are an integral part of these financial statements.

THE BARTH SYNDROME FOUNDATION, INC.
STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2008

	Program Services	Management and General	Fundraising	Total 12/31/08	Total 12/31/07
Salaries	$233,954	$34,103	$9,935	$277,992	$216,749
Payroll taxes and benefits	37,578	5,478	1,596	44,652	15,723
Total personnel services	271,532	39,581	11,531	322,644	232,472
Research grants	253,894			253,894	309,200
Professional	145,259	66,705		211,964	48,616
Telephone	2,413	5,506		7,919	5,508
Office expense	49,445	18,367	51	67,863	25,908
Printing and publications	12,734	1,365		14,099	12,480
Dues and conferences	376	5,251		5,627	8,759
Transportation	124,402	16,464		140,866	30,572
Insurance		4,965		4,965	2,043
Meals	492	1,935		2,427	8,388
Audio visual expense	32,434			32,434	0
Exhibits	1,923			1,923	6,385
Total expenses	$894,904	$160,139	$11,582	$1,066,625	$690,331

The attached notes and auditors' report
are an integral part of these financial statements.

THE BARTH SYNDROME FOUNDATION, INC.
STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2007

	Program Services	Management and General	Fundraising	Total 12/31/07
Salaries	$191,188	$25,561		$216,749
Payroll taxes and benefits	13,869	1,854		15,723
Total personnel services	205,057	27,415	0	232,472
Research grants	309,200			309,200
Professional	20,774	27,842		48,616
Telephone	2,453	3,055		5,508
Office expense	7,691	9,451	8,766	25,908
Printing and publications	8,271	2,683	1,526	12,480
Dues and conferences	4,241	4,518		8,759
Transportation	26,036	4,536		30,572
Insurance		2,043		2,043
Meals	5,987	321	2,080	8,388
Audio visual expense				0
Exhibits	6,385			6,385
Total expenses	$596,095	$81,864	$12,372	$690,331

The attached notes and auditors' report
are an integral part of these financial statements.

THE BARTH SYNDROME FOUNDATION, INC.
STATEMENT OF CASH FLOWS
FOR THE YEARS ENDED DECEMBER 31, 2008 AND 2007

	12/31/08	12/31/07
Cash Flows from Operating Activities:		
Change in net assets	($204,880)	$100,631
Adjustments to reconcile change in net assets to net cash provided by/(used for) operating activities:		
Donated stock	0	(10,395)
Realized gain on sale of investments	(1,762)	0
(Increase)/decrease in assets:		
Accounts receivable	(5,758)	(929)
Unconditional promises to give	(124,027)	335,332
Prepaid expenses	6,585	(5,998)
Increase/(decrease) in liabilities:		
Accounts payable and accrued expenses	(103)	3,531
Grants payable	(33,457)	49,276
Total adjustments	(158,522)	370,817
Net cash (used for)/provided by operating activities	(363,402)	471,448
Cash Flows from Investing Activities:		
Proceeds from sales of investments and donated stock	288,595	21,596
Purchase of investments	0	(286,990)
Net cash provided by/(used for) investing activities	288,595	(265,394)
Net (decrease)/increase in cash and cash equivalents	(74,807)	206,054
Cash and cash equivalents - beginning of year	2,317,189	2,111,135
Cash and cash equivalents - end of year	$2,242,382	$2,317,189
Supplemental data:		
Interest & income taxes paid	$0	$0

The attached notes and auditors' report are an integral part of these financial statements.

THE BARTH SYNDROME FOUNDATION, INC.
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2008 AND 2007

Note 1. Organization

The Barth Syndrome Foundation, Inc. (the "Foundation") is a not-for-profit organization incorporated under the laws of the state of Delaware on September 8, 2000 to act as a public foundation, operated for the following purposes: a) to promote awareness of Barth Syndrome; b) to educate and support physicians, research centers and organizations addressing the causes, diagnosis, treatment and cure of Barth Syndrome, and c) to assist in the support of families with children suffering from Barth Syndrome.

The Foundation is a tax-exempt organization under Section 501(c)(3) of the Internal Revenue Code. They have not been designated as a private foundation.

Note 2. Summary of Significant Accounting Policies

a. Basis of Accounting

The financial statements have been prepared on the accrual basis of accounting and accordingly reflect all significant receivables, payables, and other liabilities.

b. Basis of Presentation

The Foundation follows Statement of Financial Accounting Standards (SFAS) No.'s 116 and 117, *Accounting for Contributions Received and Contributions Made*, and *Financial Statements of Not-for-Profit Organizations*. Under SFAS No. 117, organizations are required to report information regarding their financial position and activities according to the following classes of net assets:

- *Unrestricted* – represents all activity without donor imposed restrictions.
- *Temporarily restricted* – relates to contributions of cash and other assets with donor stipulations that make clear the assets restriction, either due to a program nature or by passage of time.
- *Permanently restricted* – relates to contributions of cash and other assets whereby the assets must remain intact due to restrictions placed by the donor. The Foundation had no permanently restricted net assets at December 31, 2008 and 2007.

c. Contributions

Contributions received are recorded as unrestricted or temporarily restricted support depending on the existence and/or nature of any donor restrictions.

Support that is restricted by the donor is reported as an increase in unrestricted net assets if the restriction expires in the reporting period in which the support is recognized. All other donor-restricted support is reported as an increase in temporarily restricted net assets, depending on the nature of the restriction. When a restriction expires (that is, when a stipulated time restriction ends or purpose restriction is accomplished), temporarily restricted net assets are reclassified to unrestricted net assets and reported in the statement of activities as net assets released from restriction.

d. Donated Assets

Donated marketable securities and other non-cash donations are recorded as contributions at their estimated fair values at the date of donation.

e. Unconditional Promises to Give

Unconditional promises to give are recognized as revenues or gains in the period received and as assets or decreases of liabilities, depending on the form of the benefits received. Conditional promises to give are recognized when the conditions on which they depend are substantially met. At year end, the full amount is due within one year. These receivables have been evaluated for collectability and no allowance for doubtful accounts is deemed necessary.

f. In-Kind Contributions

Under SFAS No. 116, organizations are required to recognize contributions of services that enhance non-financial assets and require specialized skills. Many individuals volunteer their time and perform a variety of tasks that assist the Association with specific programs, campaign solicitation, and various committee assignments. These volunteer services do not meet the criteria stated above and have not been recognized in the financial statements.

g. Cash and Cash Equivalents

For purposes of financial reporting, cash and cash equivalents include cash held in banks, certificates of deposits and money market funds. There were no interest or taxes paid during the year.

h. Concentration of Credit Risk

The Foundation maintains its cash balances at institutions they consider to be credit worthy. The cash balances are insured by the Federal Deposit Insurance Corporation (FDIC) for amounts up to $250,000. From time to time, balances may exceed insured limits and at December 31, 2008, the Foundation had uninsured cash balances of $141,635.

i. Capitalization Policies

Items of property and equipment with an individual cost in excess of $5,000 are capitalized at cost. Routine maintenance and repair costs and leasehold improvements, which do not materially extend the estimated useful lives of property and equipment, are expensed as incurred.

j. Expense Allocation

The costs of providing various programs and other activities have been summarized on a functional basis in the statement of activities and in the statement of functional expenses. Accordingly, certain costs have been allocated among the programs and supporting services benefited. Management and general expenses include those expenses that are not directly identifiable with any other specific function but provide for the overall support and direction of the Foundation.

k. Management Estimates

The preparation of financial statements in accordance with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect certain reported amounts and disclosures. Accordingly, results could differ from those estimates.

Note 3. Temporarily Restricted Net assets

At December 31, 2008, temporarily restricted net assets consist of the following:

	Balance 1/1/08	Contributions	Released from Restrictions	Balance 12/31/08
Program Restrictions:				
Paula & Woody Varner Science and Medicine Fund	$188,918	$24,607	($45,431)	$168,094
Barth Syndrome Trust	19,303	0	(19,303)	0
Science and Medicine Fund	227,905	217,185	0	445,090
Total Program Restrictions	436,126	241,792	(64,734)	613,184
Time Restrictions	0	125,000	0	125,000
Total	$436,126	$366,792	($64,734)	$738,184

At December 31, 2007, temporarily restricted net assets consist of the following:

	Balance 1/1/07	Contributions	Released from Restrictions	Balance 12/31/07
Program Restrictions:				
Paula & Woody Varner Science and Medicine Fund	$89,215	$99,703	$0	$188,918
Barth Syndrome Trust	0	55,000	(35,697)	19,303
Science and Medicine Fund	0	227,905	0	227,905
Total Program Restrictions	89,215	382,608	(35,697)	436,126
Time Restrictions	300,000	0	(300,000)	0
Total	$389,215	$382,608	($335,697)	$436,126

Note 4. Commitments

Grants payable accrued of $134,843 are all due to be paid within twelve months.

Although the Foundation does not have any long-term leases, they are committed to research grants awarded subsequent to year end, up to the amount of $119,998, that are payable in 2009 and 2010.

Note 5. Investments

Securities are carried at fair market value in accordance with SFAS No. 124. At December 31, 2007, investments consisted of a United States Treasury Bill. At December 31, 2008, the Foundation did not carry any investments. At year end, the quoted market price was used as the basis of determining fair value, which also approximates the original cost.

The Barth Syndrome Foundation has been accredited by the Better Business Bureau, meeting all accreditation standards.

The Barth Syndrome Foundation is a member of the National Health Council, improving the health of all people, particularly those with chronic diseases and/or disabilities. BSF abides by all 42 of NHC's best practices.

The Barth Syndrome Foundation is a member of the Genetic Alliance.

Barth Syndrome Foundation

www.barthsyndrome.org