

# Barth Syndrome Journal

www.barthsyndrome.org

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

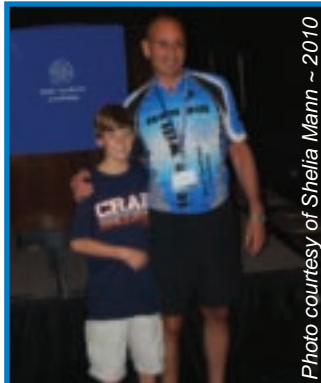


Photo courtesy of Sheila Meann ~ 2010

## The Barth Syndrome Foundation Research Grant Program: How It Matters

By Matthew J. Toth, PhD, Science Director, Barth Syndrome Foundation

With the completion of the 9<sup>th</sup> cycle of the Barth Syndrome Foundation Research Grant Program, it is a good time to reflect on its value towards accomplishing the goals of our unique organization. Before this grant program began, knowledge about Barth syndrome, its causes, or its treatment was scarce or nonexistent. The original publications by Peter Barth in the early 1980s were supplemented occasionally over the next two decades by several reports which included the identification of the defective gene—*tafazzin*. Since those early days, over 160 publications have appeared in the scientific/medical literature (125 since 2002) of which 55 acknowledge the financial support of the BSF and its affiliates. Without the support of the BSF Research Grant Program which began in 2002, how many fewer manuscripts would have been published? How many researchers would even know about this unique mitochondrial disease with its complex interplay of an enlarged and weakened heart, low white blood cell count, growth delay, and lipid abnormalities?

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## Barth Syndrome and a Winning Game Plan

By Michael Kiebish, PhD, Postdoctoral Associate, Richard Gross Laboratory, Department of Internal Medicine, Division of Bioorganic Chemistry and Molecular Pharmacology, Washington University School of Medicine, St. Louis, MO

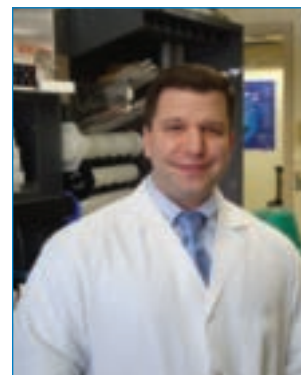


Photo courtesy of Dr. Kiebish.

When examining my role as a young scientist researching molecular strategies to treat Barth syndrome, I would like to present my experience using the analogy of a winning baseball team, being that the days of summer are upon us. My personal feelings are that the scientists involved in the Barth syndrome research community could be considered some of the most valuable players (MVPs) in their fields and the Barth Syndrome Foundation has done a superb job enticing, encouraging, and recruiting a team full of MVPs to form an ever evolving 'dream team' bound to that world series title (or cure for Barth syndrome). In every team, there are seasoned veterans, general managers, coaches, fan-favorites, designated hitters, all-stars players, and in my case—rookies. Each of the team's players channels knowledge, experience, strength, as well as novel insight into winning the game. As a team, our goal is to work together to win each game one at a time and, in our case that is in the form of making gains in scientific knowledge. In the end, we want to win enough games to take home the ultimate prize that can be shared by all team members, the community, and fans alike so we can all celebrate together.

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# Chairman's Letter

*By Stephen B. McCurdy, Chairman, Barth Syndrome Foundation*

**In the life of a child, ten years can seem like a lifetime.  
For children with a rare metabolic disease like Barth syndrome it can be.  
Our job is to fix that.**

Ten years ago parents of boys with Barth syndrome struggled to keep their sons alive. They were doing so alone, with little help from medical science and often very little guidance from their physicians. By 2001, papers had been published by Dr. Peter Barth and Dr. Richard Kelley that named the disorder, established its genetic origins and noted that its primary characteristics were cardiomyopathy, neutropenia and general muscle weakness. The papers also noted that Barth syndrome was often fatal.

The Barth Syndrome Foundation was created by a small group of parents who understood firsthand the hopelessness of facing this disease alone. They needed each other to share information and support. They needed their son's doctors to learn from each other how to diagnose and treat Barth syndrome. They needed the scientific community to study this disorder to better understand its underlying causes and develop better treatments and someday a cure. And, as is always the case, they needed money to fund it all. Above all, they knew that none of this would happen if they did not take the lead themselves. And so the Barth Syndrome Foundation was created.

Ten years later much has changed, for which we are all very grateful. And yet some things remain the same. 2010 was a year full of progress and a time full of wrenching sadness too, as we lost five boys and young men to Barth syndrome.

## The Barth Syndrome Scientific, Medical and Family Conference

Your Foundation held its Fifth International Scientific, Medical and Family Conference during the last week in July 2010 at the Renaissance at SeaWorld hotel in Orlando, Florida. The Conference opened with two days of clinics providing clinicians the chance to examine and record the medical histories of more Barth syndrome (BTHS) boys and young men than any of them will ever see elsewhere in their careers. This clinic serves at least two other purposes as well: (1) it allows the efficient collection of physiological data and historical medical information from individuals with this rare disease; and (2) it provides opportunities for patients and patient family members to meet with physicians who have a substantial experience in treating BTHS individuals. In 2010, six distinct IRB-approved protocols were participated in by many of the BTHS individuals who attended the clinic. Most of the data collected are expected to lead to publications and/or ultimately to be available through the Barth Syndrome Registry and Repository (BRR) which is open to all interested researchers.

Next, over 65 scientists, physicians, and healthcare professionals gathered to hear 26 scientists review their latest findings and to discuss the progress in BTHS research and how it may lead to better treatments. In a separate but parallel set of meetings, nearly 50 BTHS individuals with their families met to discuss issues of specific importance to their situation. This latter meeting was the largest single gathering of individuals affected by Barth syndrome the world has ever seen. In total, nearly 350 people attended this dual-track conference. The informal mixing of this diverse group of individuals at common meals, at the Poster Session and at the social function, now a traditional part of this conference series, creates a strong sense of community and strong personal dedication to a mutual cause.

## BSF Science and Medical Programs

BSF started out the year by selecting seven highly qualified research grants from the largest number of applications received by BSF, awarding a total of almost \$280,000. BSF's affiliate – BSF of Canada – provided funding for one of the grants awarded to a

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scientist in Canada. BSF's affiliate – Barth Syndrome Trust (UK & Europe) – provided funding for one of the grants awarded to a scientist in The Netherlands. BSF and its affiliates have now funded \$2 Million in research grants of up to \$40,000 each, spawning over 50 peer-reviewed scientific and medical articles published with the support of BSF.

One of the most exciting announcements made in 2010 was that a mammalian model of Barth syndrome — a “Barth mouse” — had been created with funding by BSF. This mouse and its progeny have been shown to exhibit virtually all of the genetic and clinical manifestations of Barth syndrome that have been evaluated so far and are already being used to advance valuable research including several of the research grants awarded recently in the 2010 grant cycle.

The other major breakthrough was accomplished by one of our affiliates – the Barth Syndrome Trust (BST) in the UK. Through the determined efforts of Michaela Damin, BST's President and a BSF Board member, and Dr. Colin Steward of the Bristol Royal Hospital for Children, the UK's National Health Services funded the creation of the first comprehensive, multi-disciplinary clinic dedicated to Barth syndrome in the world. This grant runs for five years and will serve affected individuals and their families throughout the UK and Europe. The Clinic will provide significantly improved care for children suffering from this rare disorder, greatly increase the exposure, experience and learning of the clinicians caring for this large group, and produce detailed medical histories and data over a five-year period for the Barth Syndrome Registry and Repository ... a triple play in American baseball (not sure what this would be in Cricket!)

You can read more about our accomplishments in Science and Medicine in our Science Director, Matt Toth's report (see pages 1;6-7 and 8-10).

### **BSF's Family Services and Awareness Programs**

BSF's Family Services team continues to find and support our growing list of affected families through the Barth Conference, our internet-based listserv, and regional outreach gatherings. The Family Services team is also available by phone 24x7 whenever a child is sick, in the emergency room or intensive care unit to provide connections to the Barth medical experts and comfort and reassurance to distraught families. For a small, geographically dispersed group, stressed to the breaking point by a serious disease, a caring community can be a real lifeline. The alternative is to be totally, deeply and irretrievably alone. Year after year, BSF Family Services provides the cement that creates a community that counts its members closer than friends and family. The programs create the opportunity to communicate, cooperate and provide mutual support. But the character of BSF is shaped more by this team, led by Shelley Bowen, than by any other single program or activity... and is the primary reason we are as healthy an organization as any truly rare disease group in the world. Nothing else would sustain us through the loss of five of our sons to Barth syndrome over the past 15 months, including Shelley's own son, Michael Bowen.

### **BSF Governance and Administration**

The BSF Board takes its governance responsibilities seriously. In 2010, BSF remained fully compliant with a host of new standards set by the IRS, the Better Business Bureau, and National Health Charities – all groups whose review and approval BSF has always received and valued. In addition, the Board created its first policy handbook covering its employees, their benefits and our mutual expectations of each other.

We are also concerned that the Board continues to attract new, dedicated, highly qualified members. Our by-laws require that the majority of Board members be directly related to someone affected by Barth syndrome. In addition, our by-laws limit the number of consecutive terms a Board member can serve to two three-year terms following the adoption of this rule. Several of our founding Board members must begin to step down from the Board beginning in 2013, including our Chairman, Steve McCurdy and Michaela

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# Chairman's Letter

*(Cont'd from page 3)*

Damin from the Barth Syndrome Trust — UK. In light of this, we have recently welcomed two new Board members – John Wilkins and Susan McCormack – and will continue to search for individuals who will bring the time, talent and treasure that we will require in the years ahead. As the first affected individual to sit on the Board, John brings a unique insight into the issues facing the Barth Syndrome Foundation and its primary constituents. Susan McCormack, whose younger daughter is a carrier of Barth syndrome and who brings a special focus on carriers, is a portfolio manager with a prominent investment management firm in Boston.

2010 also saw the departure of our first Executive Director, Linda Stundis. In the two years she was with us, Linda accomplished much including a rationalization of our international affiliate licensing agreements, the move of the BRR from the University of Florida to Children's Hospital in Boston, the development of our employee handbook, our initial approval by the Better Business Bureau, and the initial planning for the 2010 International Barth Syndrome Conference, among other things. We too, learned much from Linda and the search for her replacement is now underway.

## Conclusion

Like those of the last decade, 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 fund-raising efforts to support our programs and mission; our physicians and scientists who are successfully challenging the limitations of Barth syndrome 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 no longer causes suffering or loss of life.

## In Loving Memory:

Phillip Brown (United Kingdom) — *May 22, 2005 – September 29, 2009*  
Michael Bowen (United States) — *December 7, 1986 – December 9, 2009*  
Jamal Thomas (United States) — *August 23, 1984 – December 23, 2009*  
Zachary Basilo (Canada) — *April 28, 2009 – May 26, 2010*  
Ben Thorpe (South Africa) — *September 2, 1994 – November 17, 2010*

# BSF Welcomes Two New Board Members

*By Stephen B. McCurdy, Chairman, Barth Syndrome Foundation*



Please join us in welcoming two wonderful additions to the BSF Board of Directors. The first is John Wilkins. Being affected by Barth syndrome gives John a unique insight into the issues facing the Barth Syndrome Foundation. John recently earned an Associate in Science Degree in Computer Information Technology from Southeast Community College, and works part time as a computer consultant. John has grown up along with BSF, and in recent years has played an especially useful role in organizing conversations among older Barth boys/men both virtually and at BSF's 2010 Conference.



Our second new member is Susan McCormack, whose younger daughter is a carrier of Barth syndrome. Susan is a portfolio manager with a prominent firm in Boston. She graduated from Dartmouth College in 1986 with a degree in mathematics and received her MBA from Stanford Graduate School of Business in 1990. She is a CFA charterholder. Susan attended the 2010 Conference, and has become an active voice on BSF's listserv.

The BSF Board of Directors will continue to add new members in a thoughtful and strategic way to meet our needs in the future for expertise, leadership and fund-raising. After a decade in operation, several of our original board members will begin to step down over the next few years as their terms expire under the provisions of our by-laws, which also require that at least half of the board be comprised of family members. We are always interested in suggestions for potential new members, especially those with specialized scientific or medical knowledge or those who could be helpful with fund-raising, and we would welcome any ideas you might have.



## Meet BSF's Board of Directors



Top row:

Stephen McCurdy, Valerie (Shelley) Bowen, Randy Buddemeyer, Michaela Damin, Stephen Kugelmann

Bottom row:

Susan McCormack, Katherine McCurdy, Susan Osnos, Marcus Sernel, John Wilkins, Susan Wilkins

## BSF Board Launches the Search for a New Executive Director

*By Stephen B. McCurdy, Chairman, Barth Syndrome Foundation*

**T**he Barth Syndrome Foundation has grown rapidly, built a strong, stable foundation and has a track record of success. Despite its rapid growth, BSF remains a virtual organization with paid staff and leadership volunteers working remotely from locations across the country and around the world. If we are to continue to be successful in our mission, the Board unanimously agreed that we need a talented Executive Director who will maintain a balanced focus on families, scientists, physicians, donors, and volunteers while accelerating the progress of our programs and mission with strong leadership, organizational, communication and fund raising skills. During our last in-person Board meeting, we spent the majority of our time looking forward and defining BSF's greatest challenges over the next decade. As we see it, there are six:

- Broadening and increasing BSF's funding base, particularly among institutions and individual donors;
- Managing growth within BSF's virtual, volunteer based, global organization;
- Growing and strengthening the base of family support for BSF;
- Developing an effective strategy to accelerate clinical and scientific advances in the understanding of and treatments for Barth syndrome;
- Building more effective global programs in close coordination with our international affiliates;
- Expanding the board and continuing the transition from an operating board to a governing board.

Toward this end, the Board has hired Joe McCormack of McCormack and Associates to lead a professional search for our new Executive Director. Joe's search begins with the a detailed description of the position and its responsibilities and then moves to an equally detailed description of the ideal candidate including professional experience, skills, strengths and personal characteristics. A Search Committee consisting of Susan Osnos (Chairperson), Randy Buddemeyer, Stephen Kugelmann, Stephen McCurdy and Susan Wilkins will lead the effort initially, but the entire Board will meet any final candidates and make any hiring decisions on behalf of BSF.

BSF has posted both the position description and candidate requirements on our website at [www.barthsyndrome.org](http://www.barthsyndrome.org).

# The Barth Syndrome Foundation Research Grant Program: How It Matters

(Cont'd from page 1)

Including the 2010 cycle, the BSF has committed a total of over US \$ 2.0 million to its Research Grant Program—its largest yearly budget expenditure. The basic understanding of the complexities and pathologies of Barth syndrome is now being systematically explored by many researchers worldwide.

(Note that throughout this article, specific BSF grant awards are shown in parentheses with the PI's name and relevant BSF grant cycle.)

Perhaps the easiest research projects to show impact are those involving animal models of Barth syndrome because these genetic models are very useful in understanding the disease process and in testing new treatments. Starting with the first grant cycle, we can trace the initial development of animal models (*Strauss 2002, 2004*) which eventually culminated in a zebra fish model. A particularly valuable fruit fly model (*Ren 2004, 2006; Malhotra 2008; Xu 2009*) was then developed that shows what other genes interact with the defective *tafazzin* gene. Most recently, the mouse model was developed independently by the BSF and is being distributed to many investigators worldwide (*Khuchua 2009; Kiebish 2009; Byrne 2010; Phoon 2010; Chicco 2010*). This mouse knockdown model is still being investigated but has already shown many interesting parallels to human Barth syndrome. With the availability of the mouse model of Barth syndrome, many laboratories not previously involved with Barth syndrome research are now in a position to make contributions to our knowledge base. All of these animal models answer different questions about what Barth syndrome is, and more importantly, how this disease may be altered to make it less deadly to Barth syndrome individuals. In addition, rat disease models (*Sparagna 2006, 2008; Moreno-Quinn 2007*) that have similarities to Barth syndrome have provided insights about how simple diet additions of certain oils may impact the symptoms of Barth syndrome.

While not an animal model, the yeast model of Barth syndrome (*Greenberg 2002, 2005, 2006, 2007, 2008, 2009, 2010; Vaz 2002; McMaster 2007*) is a workhorse for understanding many of the details of what biochemical processes are disrupted by this genetic disease. The yeast system also offers the promise of screening thousands of chemical compounds (just like what pharmaceutical companies do) in order to find compounds that may alter the disease process (*McMaster 2010*).

In the same category of cellular models of disease like the yeast system are those mammalian cell lines that mimic the basic biochemical defect of Barth syndrome—the defective *tafazzin* gene. While the *tafazzin* gene produces a protein that affects a fatty substance or lipid called cardiolipin, the full functional consequences of having a damaged *tafazzin* gene are still being worked out. Researchers have focused on understanding what cardiolipin is important for (*Haines 2005; Kobayashi 2005, 2006; Vaz 2006; Epand 2007; He 2007; Pu 2009*) and how defects in *tafazzin*/cardiolipin affect the health/functioning of the cell (*Hatch 2002, 2005, 2009; De Kroon 2010; van Raam 2010*). Barth syndrome is distinctive because it was the first human disease to be characterized as having a problem with the lipid cardiolipin. Defects in cardiolipin, however, have recently been observed in common diseases such as diabetes and heart failure making Barth syndrome research particularly relevant to these other diseases.

Projects actually involving Barth syndrome individuals are exceedingly hard to perform, given the complexities and costs associated with this sort of work, but these experiments directly tell us useful clinical information. Nevertheless, several researchers have made great progress in working with Barth syndrome individuals and have contributed to our clinical picture of this disease (*Spencer 2004, 2006; Storch 2005; Mazzocco 2006; Cade 2008, 2009*). These projects have described some important clinical aspects of the disorder and have shown that the metabolism of Barth syndrome individuals is unique, which could suggest better ideas for a specific treatment. In addition, investigators of the low white blood cell count of Barth syndrome have had an especially difficult set of obstacles to overcome in this extremely important area (*Dale 2003, 2007; Esposti 2003; Kuijpers 2003, 2007*).

Because Barth syndrome is a genetic disease, the recording of genetic data to provide genomic insights has been supported by the BSF Grant Program (*Gonzalez 2002; Ma 2003; Taylor 2007*). Barth syndrome affects all races. Understanding how one's genes affect one's symptoms is important because a better understanding of the interplay of genes may hold a key to finding why some individuals do better medically than others. In addition, it is extremely important for an individual's clinical care to receive a correct diagnosis as early as possible. To address this point, investigators have gone beyond the standard genetic tests and developed novel ways to better measure *tafazzin* gene expression (*Kirwin 2007*) and to measure cardiolipin (*Xu 2003; Kulik, 2005, 2006*) in blood or tissue samples taken directly from individuals. Achieving a correct diagnosis of Barth syndrome has always been a serious problem.

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While the activities supported over the last nine years are impressive (54 grants), and the large number of researchers supported by this Research Grant Program (34 researchers) have firmly established the groundwork for making more advances in this rare disease, we need to do more. Boys and young men are still dying from Barth syndrome, even with the best medical care! Scientifically we know far more than even a few years ago—medically we need to make more of an impact. We have the tools needed to translate what we know into new ideas for treatment.

The BSF Research Grant Program started out with very few researchers even able to suggest ways to make progress on Barth syndrome research. In this last grant cycle, we had to turn down applications of merit because funds were not available. We need more good researchers. We need more support within our organization to fund applications and to implement clinical projects. We need the professional scientific/medical community to respond by funding those worthy but expensive clinical/scientific experiments that BSF-supported researchers are now applying for from the NIH and large international funding agencies.

The BSF has always committed everything it can towards advancing a treatment for Barth syndrome. The rarity of Barth syndrome continues to be a major obstacle to attracting researchers, though we work constantly to overcome this. In the beginning, there were few researchers. Now, success has cultivated many more researchers, each with his or her own good ideas waiting to be put to the test. The goals of the BSF will be realized by continuing our successful BSF Research Grant Program. As one of our young men with Barth syndrome said to the researchers attending the 2010 BSF Conference, "Please give us treatments to try, and if they don't work, we'll try again. . . . Please don't let us lose any more of our family members!" We need to follow his advice and keep on trying.



Featured are just a few of the physicians and scientists involved in Barth syndrome research.  
*Photos courtesy of individual physicians and scientists.*



# Seven Grants Awarded for BSF's 2010 Research Grant Program

By Matthew J. Toth, PhD, Science Director, Barth Syndrome Foundation

With the completion of the 2010 BSF Research Grant Program, nine annual award cycles have committed a total of US \$2.0 million to this important effort. The BSF community should take great pride that early in its beginning, the BSF Research Program has been an integral step towards fulfilling BSF's mission. The 2010 Program attracted many fine applications. The BSF, with the advice of its Scientific and Medical Advisory Board, has chosen seven to support financially. As in the previous cycle, funding of research with the new mouse model of Barth syndrome was prominent, which just underlines the usefulness of this animal model for research purposes. The BSF would like to congratulate all the 2010 awardees.



Barry J. Byrne, MD, PhD, Associate Chair Pediatrics, Director Powell Gene Therapy Center, Professor of Cardiology, University of Florida, Gainesville, FL

["Gene therapy in mouse model of Barth syndrome"](#)

Award: US \$39,820 for 1 year

Dr. Byrne and his group will perform a detailed analysis of the phenotype (traits) of the *tafazzin* knockdown mouse at both the organism/organ level and the subcellular level. His published and unpublished data show that many of the characteristics of Barth syndrome (cardiomyopathy, cardiolipin abnormalities, and perhaps neutropenia) are present in this mouse model. To demonstrate the limits of the validity of this mouse model of a human disease, they plan to study: mitochondrial viability, function, and structure; various lipid and other subcellular components; skeletal muscle abnormalities; potential neutropenia; and to continue their investigations on cardiac function using magnetic resonance imaging (MRI) techniques and electrocardiography. In addition, they will use adeno-associated viruses containing full-length human *tafazzin* genes to test if they can ameliorate the cardiac and skeletal muscle phenotypes of the mouse model in a way that directly relates to human gene-therapy possibilities.



Colin K. Phoon, PhD, Associate Professor, New York University School of Medicine, New York, NY

["Cardiomyopathy in a mouse model of Barth syndrome"](#)

Award: US \$35,600 for 2 years

Dr. Phoon and his group will be investigating the cardiac phenotype of the *tafazzin* knockdown mouse in great detail, which includes the prenatal stages of development. Dr. Phoon provided imaging data showing the heart of the mouse model of Barth syndrome can show differences at three months of age. Dr. Phoon has pioneered sophisticated imaging analysis of mouse hearts at various stages of development including in utero techniques, which he will employ in examining the cardiac pathology of this mouse model. In addition, he will investigate calcium homeostasis in these mice which is historically linked with cardiomyopathy in general. Dr. Phoon hypothesizes that Ca<sup>2+</sup> signaling is altered in these mice which may be a contributing/causative factor of the cardiomyopathies (hypertrophy, LVNC, and dilation) observed in Barth syndrome. By measuring Ca<sup>2+</sup> transients and sarcoplasmic reticulum function in myocytes isolated from these mice using fluoroscopic techniques, Dr. Phoon expects to gain evidence to support this hypothesis which could impact cardiac treatments for Barth syndrome individuals, and should help explain why the heart and the muscle are the main pathological targets of this genetic disease.



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

["Targeting cardiolipin deficiency in the \*taz\* shRNA mouse model of Barth syndrome"](#)

Award: US \$40,000 for 2 years

Dr. Chicco, in collaboration with Dr. Sparagna (a two-time BSF Research Grant recipient), will investigate the effects of four therapeutic treatments on the *tafazzin* knockdown mouse model of Barth syndrome. Building on earlier published work by Dr. Sparagna where a safflower oil (high linoleic acid) diet showed a normalized cardiolipin profile and an improved cardiac performance in a rat model of heart failure (SHHF), they will determine the effect of this same diet supplement on the mouse model of Barth syndrome at various stages of *tafazzin* deficiency: from gestation, from post-weaning (adolescence), and from restored *tafazzin* function after a period of *tafazzin* deficiency. In addition, they

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will use the mouse model to test the effects of: a compound (GW501516) known to stimulate PPAR $\beta/\delta$  function, the fatty acid oxidation inhibitor trimetazidine (Vastarel MR, an anti-angina drug), and the thyroid hormone thyroxine—all of which have been shown to alter cardiolipin parameters. They have already established a colony of the *tafazzin* knockdown mice (from Dr. Khuchua), and they have provided unpublished data to support their choices of clinically relevant compounds. Phenotypic (trait) analysis will consist of histology, gene expression profiling, mitochondria analysis, cardiac parameter analysis, serum chemistry, biochemical analysis, etc.



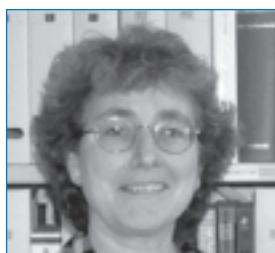
Anton I. De Kroon, PhD, Docent (Associate Professor), Utrecht University, Utrecht, The Netherlands  
“[The preferred acyl chain donor of \*Taz1p\* in the acylation of monolysocardiolipin](#)”  
Award: US \$40,000 for 2 years—funds provided by Barth Syndrome Trust (UK & Europe)

Dr. De Kroon will use the yeast system to test his hypothesis that phosphatidylserine, one of several lipid types found in biological membranes, is the predominant acyl chain donor for the *tafazzin* protein/enzyme. Dr. De Kroon provided preliminary data which showed that phosphatidylserine levels are altered in the *tafazzin* mutant. By using various yeast mutants that alter the intracellular quantities of many potential acyl chain donors (lipids) and by using the techniques of mass spectrometry and pulse radioactive labeling of lipid precursors, Dr. De Kroon will identify what precursor lipids are used by the *tafazzin* protein/enzyme to modify cardiolipin. This experimental approach is unbiased and is likely to yield novel insight into the function of *tafazzin*. In addition, Dr. De Kroon will engineer a modified *tafazzin* protein using gene-fusion technology to examine the submitochondrial locations of *tafazzin* to either the inner or outer membranes, and then he will be able to determine the relevance of this quality (inner or outer membrane localization) to *tafazzin* function.



Bram Van Raam, PhD, Postdoctoral Associate, Sanford-Burnham Medical Research Institute La Jolla, CA  
“[Caspase-8 in control of mitochondrial metabolism](#)”  
Award: US \$40,000 for 2 years

Dr. Van Raam seeks to show that a dysfunction in one of the multiple pathways controlled by the apoptosis-associated enzyme, caspase-8, is responsible for some of the metabolic abnormalities of Barth syndrome. Dr. Van Raam showed unpublished data that caspase-8 has a “pro-survival” role and a “pro-necrosis” (necroptosis) role in determining the ultimate fate of a cell. He observes that the mitochondrial abnormalities in cells from Barth syndrome individuals could be explained by defects in this apoptosis-necroptosis-survival pathway. By constructing transgenes (triple-fusion proteins) that alter the homodimerization and heterodimerization attributes of caspase-8, he will examine the subsequent effects on cellular metabolism using <sup>1</sup>H-NMR spectroscopy as well as other analytical methods. His idea is that Barth syndrome cells will resemble these theoretical caspase-8 fusion mutants by showing the same altered metabolic energy profile. If Dr. De Kroon is correct this idea may open up other ways to think about treatments for Barth syndrome individuals that are different from the apoptosis-connected ideas commonly associated with abnormalities of cardiolipin.



Miriam Greenberg, PhD, Professor and Associate Dean, Wayne State University, Detroit, MI  
“[Loss of cardiolipin leads to defective mitochondrial iron/sulfur biosynthesis and iron homeostasis](#)”  
Award: US \$40,000 for 1 year

Based on her unpublished data where the iron-associated genes are upregulated in cardiolipin yeast mutants, Dr. Greenberg seeks to investigate this phenomenon in more detail. Her hypothesis is that the loss of cardiolipin causes decreased biosynthesis of iron/sulfur cluster proteins which leads to the upregulation of genes involved with iron homeostasis. Iron/sulfur proteins make up several of the enzymatic proteins of the tricarboxylic acid cycle of the mitochondria, which have also been implicated in the subcellular pathology of Barth syndrome (i.e. arginine supplementation idea). Using electron paramagnetic resonance and Mossbauer spectroscopy, as well as inductively coupled plasma mass spectroscopy, she will examine the intracellular levels of iron in yeast cardiolipin mutants, and she will measure the gene expression of iron/sulfur mitochondrial enzymatic proteins as well as the mitochondrial import of these same proteins. In addition, Dr. Greenberg will overexpress the ISU1 and ISU2 genes in cardiolipin mutants of yeast and monitor the affect on growth. The ISU1 and ISU2 genes are implicated in the scaffolding assembly of iron/sulfur proteins, and the human gene is implicated in the Swedish-type mitochondrial myopathy which presents with exercise intolerance, fatigue, and rhabdomyolysis.

(Cont'd on page 10)

# Seven Grants Awarded for BSF's 2010 Research Grant Program

(Cont'd from page 9)



Christopher McMaster, PhD, Professor, Dalhousie University, Halifax, Nova Scotia, Canada  
"A screen for drug leads for the treatment of Barth syndrome"  
Award: US \$38,350 for 1 year—funds provided by Barth Syndrome Foundation of Canada

Dr. McMaster proposes to engineer a specialized yeast strain with a *tafazzin* deletion to screen chemical libraries of drug-like compounds and find active lead compounds that may reverse the *tafazzin* deficiency. The *tafazzin* deletion yeast strain grows poorly on a certain type of food source (restrictive media) while the wild type strain grows well. Those compounds which allow the *tafazzin* deletion yeast to grow well on the restrictive media may become lead compounds for pharmaceutical development. Dr. McMaster presented this research plan to the Centre for Drug Research and Development (CDRD) in Vancouver, BC, Canada. The CDRD leadership agreed with the viability of this approach and they will provide their drug libraries, highly trained personnel, and infrastructure for this project. Secondary screens to validate any hits and turn them into viable lead compounds will involve protein carbonylation, respiration measurements, mitochondrial membrane potential, mitochondrial protein import, protein supercomplex assembly, mitochondrial cristae formation, and the cardiolipin/monolysocardiolipin ratio. If the lead compounds are interesting pharmaceutically, then the *tafazzin* knockdown mice could be employed for more testing.

\*Photos courtesy of individual physicians and scientists.

## RNAi Webinar: Using *in vivo* Knockdown Technology to Model Human Barth Syndrome in the Mouse

A recent webinar about the *tafazzin* knockdown mouse as a model of Barth syndrome was presented by Drs. Zaza Khuchua and Barry J. Byrne. The May 31<sup>st</sup> webinar was recorded and the presentation slides are now available on the Taconic website for downloading: <http://www.taconic.com/wmspage.cfm?parm1=4101>.

## *Tafazzin* Knockdown Mouse Soon Available For Distribution From Jackson Laboratories

The BSF is pleased to report that the *tafazzin* knockdown mouse, which the BSF developed as a tool to help researchers working on Barth syndrome, will soon be available for distribution from Jackson Laboratories. Qualified researchers are encouraged to contact Jackson Laboratories to inform them of their interest in obtaining these mice (<http://jaxmice.jax.org/jaxmice-cgi/jaxmicedb.cgi?objtype=interest&scode=014648>). The data sheet for these mice is available at: <http://jaxmice.jax.org/strain/014648.html>.

# Barth Syndrome and a Winning Game Plan

(Cont'd from page 1)

**“I have combined the Barth syndrome mouse with another transgenic mouse which makes more cardiolipin synthase. In theory, this should make more cardiolipin, which is deficient in Barth syndrome. Using this approach, I can determine what cardiolipin is actually doing in Barth syndrome and figure out if there are ways to alleviate the cardiolipin problem with potential molecularly-directed pharmacological interventions. Also, the Barth syndrome mouse model allows us to predict the effects of potential gene therapy interventions ...”**

As a rookie, my aspirations are to stimulate novel ideas, incorporate cutting edge approaches, emit new-fledged energy, and additionally look up towards the more seasoned MVPs to learn the right way to hit a curve ball. All rookies have potential, but it takes a lot of time and investment spent with the batting coaches, head coach, and talking to the general manager to realize how the rookie fits into the ball club. I would have to say that the Barth Syndrome Foundation, families, Scientific and Medical Advisory Board, as well as scientific researchers all have played a dramatic role in my past, present, and knowingly in my future. My interest in Barth syndrome came from the groundbreaking work of numerous investigators who are involved with the Foundation, and their achievements attracted me to become an active participant in this clubhouse. Depending on what team you root for, the Barth syndrome scientific community definitely has players like Roy Halladay, Albert Pujols, David Ortiz, and A-Rod, with amazing players alongside whom any rookie would be more than grateful, honored, and eager to play.

Now the Barth Syndrome Foundation has not only put together a winning team and really inspired young rookies like myself, but has also given us our secret weapon to get us into the post-season. The generation of the inducible shRNA *tafazzin* knockdown mouse model allows us to be able to throw curve balls, knuckleballs, and fast balls that no one can hit on the opposing team (roadblocks in research) and it gives us an advantage so that we can hit most every pitch that comes our way. By generating such a malleable disease model that moves us closer to the human condition, we can progress at a much faster pace toward developing a better understanding of the disease and a cure. Additionally, the model can be distributed to all interested researchers to allow for a more rapid validation of different findings. Furthermore, in my case, since mouse models represent a predominant research tool in science, other mouse models can be combined with the inducible shRNA *tafazzin*

knockdown model to develop a mechanistic strategy to alleviate the symptoms, causes, and downstream effects of Barth syndrome. In my research, I have combined the Barth syndrome mouse with another transgenic mouse which makes more cardiolipin synthase. In theory, this should make more cardiolipin, which is deficient in Barth syndrome. Using this approach, I can determine what cardiolipin is actually doing in Barth syndrome and figure out if there are ways to alleviate the cardiolipin problem with potential molecularly-directed pharmacological interventions. Also, the Barth syndrome mouse model allows us to predict the effects of potential gene therapy interventions, since by manipulating the mouse model and allowing *tafazzin* to return to normal levels, this model will allow us to interpret the effects that gene therapy would have on multiple aspects of physiology and biology.

It definitely is underemphasized how much compassion and support the Barth Syndrome Foundation, and especially the youngest fans rooting in the grandstands, provide to its players in the field. I also believe that the rookies in the field sometimes hear the fans' screams and cheers the loudest. I think I received that experience personally by getting to know some of the boys and young men as well as the families at the Barth Syndrome Conference last July in Orlando. Whether they know it or not, I am one of their biggest fans as well.

In all, this unbridled team spirit, as well as support provided by the organization as a whole, offers a winning strategy for both the scientists, families, and affected individuals. I also feel that having faith in some of the rookies, by awarding grant seed money, provides the grounding and hope that we will have the best season of our lives. This is not for the players' sake, but for the team as a whole, because in this game that we are playing, you only have to win the World Series once to redeem yourself, and we all know how much that would mean to all of us this season (Sorry Cubs fans).



## 2011 REQUEST FOR RESEARCH PROPOSALS

The Barth Syndrome Foundation, Inc. (BSF) and its international affiliates are pleased to announce the availability of funding for basic science and clinical research on the natural history, biochemical basis, and treatment of Barth syndrome. BSF's Research Grant Program now allows young, non-tenured investigators to include in their submitted budget up to 75% of the total grant amount as PI salary. We encourage all investigators at every professional level to submit their best ideas for advancing the state of knowledge about Barth syndrome so that progress can be made in finding a specific treatment or cure for this unusual mitochondrial disease. There are no geographical limitations to this funding.

### Background

Barth syndrome (BTHS) is a serious X-linked genetic condition associated with cardiomyopathy, neutropenia, skeletal muscle weakness, exercise intolerance, growth delay, and diverse biochemical abnormalities (including defects in mitochondrial metabolism and phospholipid biosynthesis). Because many clinical and biochemical abnormalities of Barth syndrome remain poorly understood, we are seeking proposals for both basic science and clinical research that may shed light on any aspect of the syndrome. We are determined to find improved treatments—and ultimately a cure—for this rare and under-diagnosed disorder.

### Types of Proposals Sought

We are interested in providing “seed grant funding” to young investigators as well as attracting experienced investigators new to the field of BTHS basic science or clinical research. We anticipate that these funds will be used for the testing of initial hypotheses and the collection of preliminary data leading to successful long-term funding by the National Institutes of Health (NIH) and other major granting institutions around the world.

### Deadline

The deadline for submission of completed research grant applications from interested researchers is October 31, 2011. Grants will be awarded in early March, 2012.

**For more information**, visit BSF's Science & Medicine Research Grant Process webpage at (<http://www.barthsyndrome.org/english/View.asp?x=1635>).

## Going Places — The Barth Syndrome Registry and Repository

*By Amy Roberts, MD, Co-Principal Investigator, Barth Syndrome Registry and Repository, Boston, MA; Director, Cardiovascular Genetics Research Program; Associate in Cardiology, Children's Hospital Boston; and Carolyn Spencer, MD, Co-Principal Investigator, Barth Syndrome Registry and Repository, Boston, MA; Pediatric Cardiology, East Carolina University, Greenville, NC*

### A Vital Link for Researchers

The Barth Syndrome 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. To date, several 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 fibroblast cell lines that will eventually be stored at Johns Hopkins Cell Center and made available to researchers.

### What's Happening to the BRR

Some of the BRR has been moved from the University of Florida (UF) to Children's Hospital Boston (CHB) under the guidance of Dr. Amy Roberts (Co-Principal Investigator) and Judith Geva (Study Coordinator). Dr. Carolyn Spencer remains a Co-Principal Investigator. The University of Florida remains integrally involved in the BRR; this is where the database of information is stored and updated under the guidance of Dr. Barry Byrne and Connie Nixon.

*(Cont'd on page 13)*

(Cont'd from page 12)

The DNA of BRR veterans, who enrolled prior to the 2010 Conference and signed a consent form, has been moved from UF to CHB. The DNA of BRR rookies, who enrolled at the 2010 Conference or after, has been sent directly to the Roberts lab in Boston for storage. Shelley Bowen has been tremendously helpful as a liaison for parents interested in becoming a part of the BRR.

Freezer Works™, a new software system, is now up and running allowing the Boston samples to be bar coded and carefully catalogued for ease of sample storage, retrieval, and sharing. Lymphoblast cell lines (cell lines derived from blood samples) are now held at the Johns Hopkins Cell Center and are also available for research purposes.

### The BRR at the 2010 Conference

BRR veterans, already enrolled in the BRR, completed a yearly update form for the 2010 Barth Syndrome Conference to provide medical history since their previous questionnaire. BRR rookies, enrolling then for the first time, completed a questionnaire that included demographic information, medical history (cardiac, hematologic, neurological, musculoskeletal, infectious, other), initial diagnosis details, history of hospitalization, review of symptoms, family medical history, developmental history, education history, history of use of assistive devices, medications (past and current), pregnancy and birth history, and history of genetic testing. In addition, medical records were collected to obtain information from echocardiogram reports, complete blood count results, growth data points, electrocardiograms (ECGs), electrophysiologic (EP) studies, bone marrow biopsies, exercise tests, heart catheterizations, chest x-rays and the outcomes of clinic visits to cardiology, genetics, hematology, and neurology.

### Next Steps for Researchers Interested in Using the BRR

Please visit the BRR website [www.peds.ufl.edu/barthsyndromeregistry/](http://www.peds.ufl.edu/barthsyndromeregistry/) for more information. DNA, cell lines and some biological samples are available to be used, and data are available for inquiry.

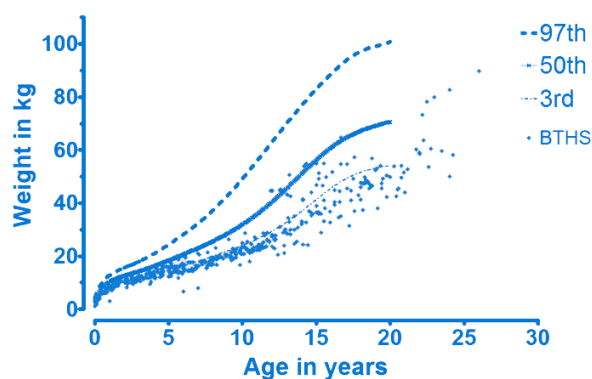
### Next Steps for Family Members to Contribute to the BRR

- If you want to know how to enroll in the registry;
- If you are already enrolled and want to update your medical information;
- If you are enrolled prior to the 2010 meeting and have not yet signed a consent form to have your DNA samples forwarded to the Roberts lab.

Judith Geva, BRR Study Coordinator, is awaiting your e-mail, [judith.geva@cardio.chboston.org](mailto:judith.geva@cardio.chboston.org) or call, 617-355-4979 (for outside North America call 1-617-355-4979) or visit the BRR web site at [www.peds.ufl.edu/barthsyndromeregistry/](http://www.peds.ufl.edu/barthsyndromeregistry/).

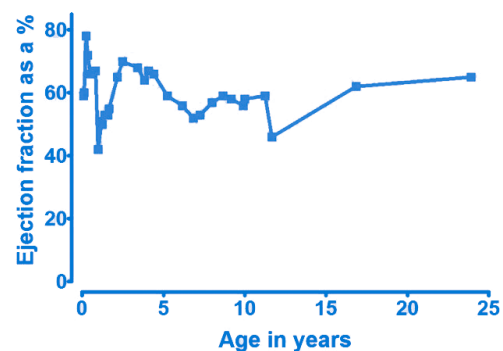
As physicians, investigators, patients and families working together, we will continue to make this resource even more robust and more valuable, and thus will help accelerate progress being made in Barth syndrome.

**Weight vs. age graph for males**



**Weight vs. age of males.** The weight of males is plotted as a function of age in the above graph. The solid curve corresponds to the 50<sup>th</sup> percentile of all US males, while the thick-dotted curve and thin-dotted curve depict the population extremes corresponding to the 97<sup>th</sup> and 3<sup>rd</sup> percentiles, respectively. The data from all the BRR subjects is plotted as small blue diamonds. One can easily notice that BTHS individuals are at the lower percentiles of the population, especially before puberty.

**Subject 80: Ejection fraction vs. age**



**Subject #80: Ejection fraction vs. time.** The heart ejection fraction of subject #80, who is enrolled in the BRR, is plotted as a function of age in the above graph. In unaffected individuals the heart ejection fraction should be above 50% and not substantially change over this age range.

# High Mortality in Past Generations

## From Heartbreak to Hope

By Terry and Dick Dannels, *Grandparents of Jack (BTHS Diagnosed Individual, Age 18 )*, New Jersey



(L-R) Terry and Dick's grandchildren: Kelsey, Jack, Isabella, and Olivia. (Photo courtesy of Terry Dannels ~ 2010.)

I love Barth conferences. They are the essence of hope. I am awestruck during each conference as I contemplate my journey from hope-less to hope-full.

It all began when my husband, Dick, our daughter, Evelyn, and I welcomed our son, Ricky, in June 1963. Ricky was born at term but was only 3 pounds 13 ounces at birth, immature rather than premature. On day three he had an episode of "failure," was supported, and came home at 5 pounds on no medications or treatments of any kind. Ricky ate poorly, slept continually and gained slowly. Then, in October we lost our beloved son to heart failure, secondary to "Endocardial fibroelastosis probably due to a virus."

Thinking the worst was behind us, we had two more children, Liz and a son. Christopher was born in July of 1966 at term, yet he weighed only 3 pounds 15 ounces. Just like his brother, he failed at three days, was supported, and began to gain. At our insistence a cardiologist was called in and pronounced his heart fine.

At home, our little son didn't eat well, didn't meet growth parameters, had frequent fevers, and skin infections. We went from doctor to doctor, and at age four months Christopher was admitted to the children's hospital with "Failure to thrive." I could tell that this diagnosis was translated to "The mother has a problem" by the attitudes around me and the doctor saying, "He will probably improve in another environment." I really did not care what anyone thought as long as they helped my baby.

Tests done in the hospital showed low to zero neutrophil count, poor heart function, enlarged liver and no explanation. No one had ever seen anything like this, except us. Students, interns, residents and attending physicians were intrigued. Dick and I were desperate. We said, "There must be someone who can help us. There must be somewhere we can go for help. Can you give us some where to find other parents like us?" All answers were "No."

We brought our young son home on Lanoxin. Amazingly, just on this one medication Christopher began to gain and grow, still having fevers, mucous membrane and skin infections, but generally catching up. He started walking at 24 months, playing with his sisters and the neighbor kids, happy, delighted and delightful. At 28 months, Christopher was pronounced cured and the digitalis stopped. One week later, our beautiful boy succumbed to heart failure and digitalis toxicity during re-digitalization in the ICU. It all seemed so hopeless.

Fast forward thirty years: Liz, John, and Kelsey Higgins welcome our first and only grandson, Jack. He is a beautiful baby apparently strong and healthy, but on the third day, something is wrong, "probably septic." I hurried to the neonatologist and told him the whole story. He listened and called in a cardiologist who examined Jack and did an echo which showed extremely poor heart function. With this focus Jack, now 18, received appropriate treatment and after a month came home on medication only.

Within the year we had learned the long-sought diagnosis, Barth syndrome. Liz and John were able to connect with other families by phone and email. Seven years later, in the summer of 2000 in Baltimore, we met our Barth Family. I remember noting how quickly the boys related to each other. I even thought they looked alike. After 37 years, Dick and I were able to speak with other families who had shared like experiences. Best of all, this meeting gave us hope.

With every conference we learn more, talk more, meet more, and are more grateful and more hopeful. We have learned about carriers and the availability of testing for our daughters and granddaughters, Kelsey, age 19, Olivia, age 12, and Isabella, age 12. We have learned about GCSF to minimize effects of neutropenia, and how adjustments in diet can support muscle strength and even reach the roots of the disorder. The Barth Syndrome Foundation has been established to support scientific research and raise awareness for early diagnosis.

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(Cont'd from page 14)

BSF also has a Family Listserv. I very seldom correspond but I read every entry. In fact due to a computer glitch I get two copies of each entry and I read them both. I whoop and celebrate the successes; I pray and pray for those waiting; I cry twice for the losses. Yes, there are still losses to this syndrome, very painful losses. Even so, we journey together toward a cure for which we are ever hopeful.

## Cameron Loves Life

By Donna, Mother of Diagnosed Son, Australia



Donna, Fraser, Jordan, and Cameron (BTHS, age 12).  
(Photo courtesy of Amanda Clark ~ 2010.)

Barth syndrome, although we didn't know, has a long family history with us. My knowledge of it starts back with my Nan. She had two girls and a boy and then lost three boys in a row. Failure to thrive they called it, and from what I can gather Nan felt very guilty about these little boys and she suffered depression and was never the same after. Aunty then had a little boy and he never grew properly. He died around six months of age and was barrel chested. He had poor heart function and my aunt had to crush up medicine for him. My mum then had a boy and by this stage she had an idea that there may be something familial going on. My brother, Martin, never went home. He fought for 10 weeks before he died and left my parents heartbroken. The doctors told my parents after the autopsy that my brother had the heart of a 70 year old man and they called it fibroelastosis. My parents consulted a geneticist who advised them not to have any more children and to consider adoption. He told them that whatever this illness was it should have skipped a generation

after my grandparents but obviously it hadn't. We know that this information is incorrect now, but my parents lived in the hope that if they managed to have children this disorder would not be carried by them. They took a gamble and had me and then my sister. We have since learned that we have distant family in the UK who also have children with Barth syndrome.

In 1998 I fell pregnant with Cameron. It was a relatively normal pregnancy other than vomiting 24/7 for 24 weeks. Cameron was born two weeks early and was tiny at 5 pounds 12 ounces. Given our family history we saw a cardiologist and he had an echocardiogram. Cameron's function was on the low side of normal and we made an appointment for another checkup in a couple of months. At nine weeks our world turned upside down.

Cameron was having trouble feeding and seemed snuffly. We went to our family doctor who promptly sent us to the hospital where we found Cameron was in heart failure. We were devastated. We were also very fortunate however as the cardiologist had recently read a paper on Barth syndrome, and given Cameron's presenting symptoms and my family history, he thought it very likely that this is what he had. Bloods were sent away and it was 18 months before we got a confirmation. In the meantime, we consulted a geneticist who told us that with my family history we shouldn't expect him to live out of infancy and as you can imagine we were devastated.

We found the Barth Syndrome Foundation and with that we found instant friends, family, and acceptance. It can be a lonely world when nobody understands what you are going through and fighting for. We attended our first conference in 2006, and it was a very emotional and confronting experience, but it is one we have never regretted. We laughed, cried, and learned so much about Barth syndrome. When you are a parent of a child with a rare disorder you need to learn as much as you can as you are your child's best advocate. Doctors have lots of patients but we have only one Cameron and we are grateful for all of the research and hard work the Foundation has undertaken.

Cameron is now 12 years old. He reached his milestones late but he reached them. His heart has been stable and he has only recently started having trouble with neutropenia. He has managed up until now to attend primary school full time but as the grades get higher he struggles more to keep up and the fatigue is greater. He uses a wheelchair for long distances and he is now finding that his low muscle tone is impacting on his friendships as he cannot keep up. He was recently told that

(Cont'd on page 16)

# High Mortality in Past Generations

(Cont'd from page 15)

he wasn't getting an invite to a birthday party as the child's mother had said he couldn't be invited because of "his medical problem." It is so heartbreaking at times. You just want your son to fit in and be 'normal' and happy. Cameron loves the conferences so much because, as he says, "When you are there "people just get it." As much as Cameron hurts, he always manages a smile.

We were so lucky and blessed to get a diagnosis early and we are so lucky and blessed to have Cameron here with us today. He is a typical 12 year old, cheeky and a bit too smart for his own good. However, Barth syndrome has given him empathy and insight far greater than his years — but with that comes worry beyond his years also. Cameron loves life and lives it to the full. Most days he tells me, "I love my life, Mum." I just wish my Nan was here to see him.

## Newly Revised Healthcare Professional Brochure

Inserted in this issue of the Barth Syndrome Journal is a copy of an informative new brochure about Barth syndrome, written by people at BSF and reviewed by the clinical members of our international Scientific and Medical Advisory Board (SMAB). It provides a good overview of this complicated syndrome from a number of angles. One important section lists a summary of some of the unusual clinical complexities that can arise (sometimes very quickly) as a result of the multi-system nature of this disorder. These two pages can be particularly useful for treating physicians and for patients during first visits with new doctors. Additionally, it can be vitally important in an Emergency Room when a physician unfamiliar with Barth syndrome is suddenly asked to care for a patient with the disorder.

There is also a section highlighting published journal articles that detail much of the current clinical knowledge about the syndrome. Physicians who would like to know more about a specific aspect of the disorder, or scientists trying to understand how far research has taken us to date, will find this of great interest.

If anyone — family, physician, scientist or donor — would like some additional hard copies, please contact Lynda Sedefian at [lynda.sedefian@barthsyndrome.org](mailto:lynda.sedefian@barthsyndrome.org). The brochure is also available on the BSF website at [www.barthsyndrome.org](http://www.barthsyndrome.org). We have received very favorable comments about the usefulness of this brochure, and I think all will agree that this is an extremely valuable resource.

## Barth Syndrome in the US News

### Mother of Barth syndrome patient holds pajama drive

By Scott Swan | WTHR.com | Posted: May 20, 2011

View a segment from WTHR 13 about Barth syndrome and Henry's Pajama Program.

### Ft. Wright baby fights for life and new heart

By Carol Williams | WCPO.com | Posted: Friday, April 29, 2011

Featuring one of our Barth families and their son's heart transplantation journey.  
[http://www.wcpo.com/dpp/news/health/healthy\\_living/ft.-wright-baby-fights-for-life-and-new-heart](http://www.wcpo.com/dpp/news/health/healthy_living/ft.-wright-baby-fights-for-life-and-new-heart)

### Young man battles genetic heart disorder

By Cynthia Billhartz Gregorian | STLtoday.com | Posted: Wednesday, February 23, 2011

To determine if exercise therapy could be a potential life-improving therapy for Barth syndrome (BTHS), W. Todd Cade, PhD from Washington University in St. Louis, Missouri will explore the benefits and risks associated with exercise treatment in Barth syndrome.  
[http://www.stltoday.com/lifestyles/health-med-fit/fitness/article\\_65cd9a9e-74e3-54da-8637-a8f5ff07683a.html](http://www.stltoday.com/lifestyles/health-med-fit/fitness/article_65cd9a9e-74e3-54da-8637-a8f5ff07683a.html)

**Barth syndrome (BTHS) clinical research has made it to the "big time,"** as a current BTHS study ([Exercise Training in Barth Syndrome](#); Principal Investigator: William T. Cade, PT, PhD, Washington University School of Medicine) is now included on [ClinicalTrials.gov](http://ClinicalTrials.gov)—the most prominent website for such projects. For more information, please visit <http://clinicaltrials.gov/ct2/show/NCT01194141>.

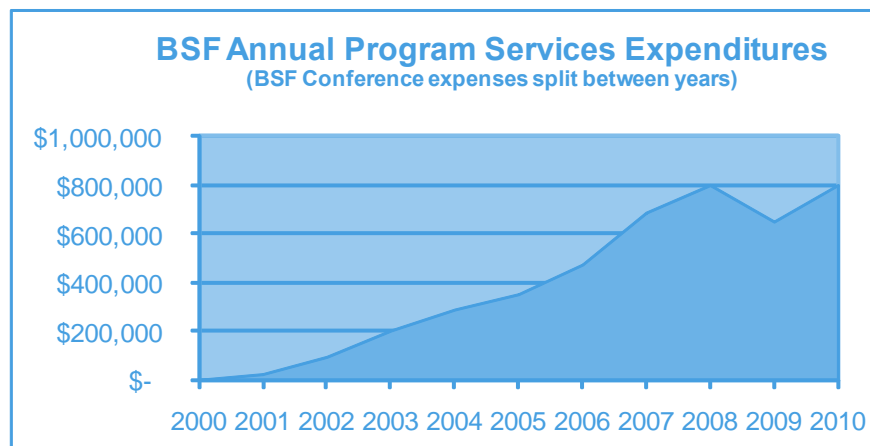
# 2010 — A Challenging Year for BSF

By Stephen B. McCurdy, Chairman, Barth Syndrome Foundation

Like most charities, Barth Syndrome Foundation had a difficult year in 2010 where money was concerned. We ended the year with a deficit of \$271,861 having raised \$713,988 in contributions. On the positive side, we funded \$253,894 in research grants and our most heavily attended International Barth Conference at a cost of just over \$200,000 including Poster stipends and speaker travel.

The Barth Syndrome Foundation, Inc. Statement of Activities For the Years Ended December 31					
			2010	2009	2008
<b>Public Support and Revenue</b>					
Contributions			\$ 769,756	\$ 694,771	\$ 727,957
Other			\$ 25,375	\$ 43,592	\$ 133,788
<b>Total Support and Revenue</b>			<b>\$ 795,131</b>	<b>\$ 738,363</b>	<b>\$ 861,745</b>
<b>Expenses</b>					
Program Services			\$ 902,379	\$ 551,816	\$ 894,904
Management and General			\$ 131,225	\$ 161,480	\$ 160,139
Fund Raising			\$ 33,388	\$ 45,652	\$ 11,582
<b>Total Expenses</b>			<b>\$ 1,066,992</b>	<b>\$ 758,948</b>	<b>\$ 1,066,625</b>
<b>Change in Net Assets</b>			<b>\$ (271,861)</b>	<b>\$ (20,585)</b>	<b>\$ (204,880)</b>
<b>Net Assets - Beginning of Period</b>			<b>\$ 2,204,320</b>	<b>\$ 2,224,905</b>	<b>\$ 2,429,785</b>
<b>Net Assets - End of Period</b>			<b>\$ 1,932,459</b>	<b>\$ 2,204,320</b>	<b>\$ 2,224,905</b>

What allows BSF to continue to fund our programs despite a shortfall in fund raising is what our accountants call our "Net Assets" — essentially prior year's surplus funds saved and held in reserve for just such a year. We had \$1,932,459 in Net Assets on our Balance Sheet at the end of 2010 which allows us to continue to fund critical science and medicine programs such as the Barth Syndrome Registry and Repository (BRR) and the special projects such as the development of the Barth mouse, in addition to the Research Grant program and the biennial Barth Conference. Our annualized Program Expenditures have peaked at around \$800,000.



(Cont'd on page 18)



# 2010 A Challenging Year for BSF

(Cont'd from page 17)

Still, it is imperative that all who believe in and support the work of BSF help us to find ways to raise additional money. All of our fund raising continues to come from friends and family members and from family foundations closely associated with them, from fund-raising efforts both large and small, and from donors whose gifts range from \$5 to \$100,000. In 2010 we received 874 donations from 571 individuals and institutions. The majority of our funds in 2010 came from the efforts of 13 Barth families, supplemented by a number of additional families who asked that gifts be made to BSF in memory of a loved one who had passed away—an incredible act of generosity in a time of great sadness.

BSF's Fund Raising Families - 2010	
McCurdy	Baffa
Buddemeyer	Oldewage
Sernel	Fairchild
Wilkins	Holly
Bowen	Higgins
Kugelmann	Brody
Osnos	

If the Barth Syndrome Foundation is to continue in our quest to understand the causes of Barth syndrome, insure the accurate diagnosis of every child affected, encourage the development of effective treatments and find a cure for this disorder, we need to add to this list of leaders! The McCurdys and Wilkins send out a simple letter each year to their friends and family explaining why they are devoted to our cause and asking that everyone include BSF in their charitable giving. The Kugelmann and Buddemeyer families sponsor golf tournaments and raise awareness and money under the sun in Florida. The Higgins family has held a fun-filled bowling tournament for years, giving their friends an extra excuse to give to BSF.



Henry proudly displays his G4.5 t-shirt!  
(Photos courtesy of Tiffini Allen ~ 2010.)

This year already, Tiffini Allen has joined the ranks of BSF fund-raising families, organizing a **Hey Hey Henry** Chicago Cubs Rooftop fundraiser and netted over \$9,000. She made and sold t-shirts that had "G4.5" written on one side, and as we all know, an explanation on the other describing the *tafazzin* gene, also called G4.5 on the "X" chromosome. Tiffini topped that off with a Barth Walk along a canal in Indianapolis next to the hotel where the summer Barth outreach event will be held and raised an additional \$900, and her Mom and sisters are organizing a bowling event for the fall. No wonder the local Indianapolis TV station wanted to interview Tiffini and Henry for the evening news! You can bet that her donors and their friends will be looking forward to next year's events!

The **Month of May** (MoM) family awareness and fund-raising effort has been given new life on the BSF Family listserv. Every few days, another family told their own story of diagnosis and learning to live with Barth syndrome. Each

story chronicled a journey from initial fear, confusion and hopelessness to the discovery of a warm, informed and positive family within BSF. The value of a supportive group like BSF is so clear in these stories, as is the importance of fund raising to insure that the families who are affected have more and more medical options available to them as time goes by, and more and more families with whom to share their stories and information!

(Cont'd on page 19)

(Cont'd from page 18)

News has just reached us that the Baffa family and friends are holding a **Baffa Beach Bash** to kick off the summer on **June 24<sup>th</sup>** with a little fun, music, great food and dancing. Clearly, if you have friends who like to have fun and any inclination to have a party, you too can raise money and awareness for BSF!

Finally, on **July 24<sup>th</sup> in Lake Placid, New York**, six of BSF's Ironmen and Ironwomen will be racing to complete the **Ironman Triathlon** as members of Team Will – BSF's International Triathlon Team. Our Ironmen include Coach Gary Rodbell, Ghent Lummis, Matt Karp, Laura Azar Kuhn, Heather Segal, Stefan Tungez, and Jaime Jofre. Already in 2011, Ghent has completed the Texas Ironman for Team Will and Stefan completed "Sharkfest, Escape from Alcatraz" wearing the Barth Blue Jersey. The team has been training for some time now and fund raising has already begun. Anyone who can make it to Lake Placid on July 24<sup>th</sup> is welcome to come and cheer on our Barth Blue Ironmen and Women!



Top Row: A few of our Team Will members (L-R) Gary Rodbell, Ghent Lummis, Matt Karp, and Heather Segal.

Bottom Photo: Coach Gary routing on members of Team Will during Ironman Florida 2010.

*Photos courtesy of BSF and members of Team Will.*



All these efforts are greatly appreciated on many levels. Not only do they garner important funds for our Foundation's work, but they also raise awareness of our little known and thus rarely diagnosed disease. So, as a result, our mission is advanced in several critical ways. Thank you to all who have been involved so far in any way, and thank you in advance to those who will join with even greater vigor this year.

# Awareness of Barth Syndrome is Growing Exponentially

There has been a significant increase in Barth syndrome (BTHS) related peer-reviewed journal articles published. To date, there have been **55** articles published on BTHS research conducted with the support of BSF and/or BSF affiliate funding (denoted below with †) and publications that acknowledge biological samples and/or information from Barth families, the Barth Syndrome Registry and Repository, and/or BSF affiliates (denoted below with ▼). Listed below are articles relevant to BTHS that have been added to BSF's library since the last issue of the Barth Syndrome Journal. To view the complete bibliography on BTHS, please visit [www.barthsyndrome.org](http://www.barthsyndrome.org).

1. Zhang L, Bell RJA, Kiebish MA, Seyfried TN, Han X, Gross RW, Chuang JH. [A Mathematical Model for the Determination of Steady-State Cardiolipin Remodeling Mechanisms Using Lipidomic Data](#). PLoS ONE 6(6): e21170. (Abstract)
2. Garratt V, Riddiford D, Steward C, Tsai-Goodman B, Newbury-Ecob R. [What is Barth syndrome?](#) Midwives Magazine: Issue 4: 2011. ▼
3. Acehan D, Malhotra A, Xu Y, Ren M, Stokes DL, Schlame M. [Cardiolipin Affects the Supramolecular Organization of ATP Synthase in Mitochondria](#). Biophys J. 2011 May 4;100(9):2184-92. (PubMed Abstract) †
4. Pei W, Kratz LE, Bernardini I, Sood R, Yokogawa T, Dorward H, Ciccone C, Kelley RI, Anikster Y, Burgess HA, Huizing M, Feldman B. [A model of Costeff Syndrome reveals metabolic and protective functions of mitochondrial OPA3](#). Development 2010 Aug 1;137(15):2587-96. (PubMed Abstract)
5. Rosca M, Minkler P, Hoppel CL. [Cardiac mitochondria in heart failure: Normal cardiolipin profile and increased threonine phosphorylation of complex IV](#). Biochim Biophys Acta. 2011 Feb 11. [Epub ahead of print] (PubMed Abstract)
6. Jameson E, Morris AAM. [Mitochondrial disease – a review](#). Paediatrics and Child Health, Volume 21, Issue 2, February 2011, Pages 80-83. (Abstract)
7. Kuroda T, Tani M, Moriguchi A, Tokunaga S, Higuchi T, Kitada S, Kuge O. [FMP30 is required for the maintenance of a normal cardiolipin level and mitochondrial morphology in the absence of mitochondrial phosphatidylethanolamine synthesis](#). Mol Microbiol. 2011 Feb 9. doi: 10.1111/j.1365-2958.2011.07569.x. [Epub ahead of print] (PubMed Abstract)
8. Claypool SM, Whited K, Srijumnong S, Han X, Koehler CM. [Barth syndrome mutations that cause tafazzin complex lability](#). J Cell Biol. 2011 Feb 7;192(3):447-62. (PubMed Abstract)
9. Maniti O, Cheniour M, Lecompte MF, Marcillat O, Buchet R, Vial C, Granjon T. [Acyl chain composition determines cardiolipin clustering induced by mitochondrial creatine kinase binding to monolayers](#). Biochim Biophys Acta. 2011 Jan 19. [Epub ahead of print] (PubMed Abstract)
10. Bird SS, Marur VR, Sniatynski MJ, Greenberg HK, Kristal BS. [Lipidomics Profiling by High-Resolution LC-MS and High-Energy Collisional Dissociation Fragmentation: Focus on Characterization of Mitochondrial Cardiolipins and Monolysocardiolipins](#). Anal Chem. 2010 Dec 30. [Epub ahead of print] (PubMed Abstract)
11. Osman C, Voelker DR, Langer T. [Making heads or tails of phospholipids in mitochondria](#). J Cell Biol. 2011 Jan 10;192(1):7-16. (PubMed Abstract)
12. [Mouse model of Barth syndrome](#). SciBX 3(47); Dec 9 2010. (Nature Abstract) †
13. Jalmar O, Garcia-Saez AJ, Berland L, Gonzalez F, Petit PX. [Giant unilamellar vesicles \(GUVs\) as a new tool for analysis of caspase-8/Bid-FL complex binding to cardiolipin and its functional activity](#). Cell Death and Disease 1, e103 (2 December 2010). (Nature Abstract) ▼
14. Soustek MS, Falk D, Mah C, Toth M, Schlame M, Lewin A, Byrne B. [Characterization of a Transgenic shRNA Induced murine model of Tafazzin Deficiency](#). Hum Gene Ther. 2010 Nov 23. [Epub ahead of print] (PubMed Abstract)
15. Hershberger RE, Morales A, Siegfried JD. [Clinical and genetic issues in dilated cardiomyopathy: A review for genetics professionals](#). Genet Med. 2010 Nov;12(11):655-67. (PubMed Abstract)
16. Yoda E, Hachisu K, Taketomi Y, Yoshida K, Nakamura M, Ikeda K, Taguchi R, Nakatani Y, Kuwata H, Murakami M, Kudo I, Hara S. [Mitochondrial dysfunction and reduced prostaglandin synthesis in skeletal muscle of Group VIB Ca<sup>2+</sup>-independent phospholipase A<sub>2</sub>gamma-deficient mice](#). J Lipid Res. 2010 Oct;51(10):3003-15. Epub 2010 Jul 12. (PubMed Abstract)
17. Takahashi H, Hayakawa T, Ito K, Takata M, Kobayashi T. [Small-angle and wide-angle X-ray scattering study on the bilayer structure of synthetic and bovine heart cardiolipins](#). 2010 J. Phys.: Conf. Ser. 247 012021 (Abstract) †
18. Lu B, Xu FY, Taylor WA, Feingold KR, Hatch GM. [Cardiolipin Synthase-1 mRNA Expression Does Not Correlate with Endogenous Cardiolipin Synthase Enzyme Activity In Vitro and In Vivo in Mammalian Lipopolysaccharide Models of Inflammation](#). Inflammation. 2010 Jul 23. [Epub ahead of print] (PubMed Abstract)
19. Rea SL, Graham BH, Nakamaru-Ogiso E, Kar A, Falk MJ. [Bacteria, yeast, worms, and flies: exploiting simple model organisms to investigate human mitochondrial diseases](#). Dev Disabil Res Rev. 2010 Jun;16(2):200-18. (PubMed Abstract)
20. Ashworth M. [Cardiomyopathy in Childhood: Histopathological and Genetic Features](#). Pathology Journal, 2010, 4, 80-93. (Abstract)
21. van Raam BJ, van Bruggen R, Tool AT, Jansen MH, Warris A, Jolles S, Kuijpers TW. [Nuclear factor- \$\kappa\$ B is not essential for NADPH oxidase activity in neutrophils from anhidrotic ectodermal dysplasia patients](#). Blood. 2009 May 21;113(21):5362-3. No abstract available. (PubMed Abstract)
22. Zimmerman RS, Cox S, Lakdawala NK, Cirino A, Mancini-DiNardo D, Clark E, Leon A, Duffy E, White E, Baxter S, Alaamery M, Farwell L, Weiss S, Seidman CE, Seidman JG, Ho CY, Rehm HL, Funke BH. [A novel custom resequencing array for dilated cardiomyopathy](#). Genet Med. 2010 May;12(5):268-78. (PubMed Abstract)
23. Lenaz G, Genova ML. [Structure and organization of mitochondrial respiratory complexes: a new understanding of an old subject](#). Antioxid Redox Signal. 2010 Apr 15;12(8):961-1008. Review. (PubMed Abstract)
24. Kato A, Kawamata N, Tamayose K, Egashira M, Miura R, Fujimura T, Murayama K, Oshimi K. [Ancient ubiquitous protein 1 binds to the conserved membrane-proximal sequence of the cytoplasmic tail of the Integrin  \$\alpha\$  Subunits That Plays a Crucial Role in the Inside-out Signaling of  \$\alpha\$ IIb \$\beta\$ 3](#). J Biol Chem. 2002 Aug 9;277(32):28934-41. Epub 2002 May 31. (PubMed Abstract)
25. Ellinor PT, Milan DJ, MacRae CA. [Metabolic gene defects and risk of arrhythmia](#). Heart Metab. 2006;33:9-12. (Abstract)



# Research Initiatives Relevant to Barth Syndrome

The following ongoing research initiatives at organizations other than BSF are particularly relevant to Barth syndrome:

## National Institutes of Health (NIH)

### NIAMS Small Grant Program For New Investigators (R03)

Program Announcement (PAR) Number: PAR-09-031

Opening Date: January 23, 2009  
Application Receipt/Submission Date(s): Multiple dates  
Expiration Date: October 25, 2011  
<http://grants.nih.gov/grants/guide/pa-files/PAR-09-031.html>

Purpose: The Division of Musculoskeletal Diseases of the NIAMS supports fundamental research in bone, muscle and connective tissue biology as well as research aimed at improving the diagnosis, treatment, and prevention of diseases and injuries of the musculoskeletal system and its component tissues. Key public health problems addressed by this research include osteoporosis, osteoarthritis, orthopaedic disorders and injuries, including sports medicine and regenerative medicine and the muscular dystrophies. (This is an RO3 grant program which is designed to help young investigators.)

### Pilot and Feasibility Clinical Research Grants in Diabetes, Endocrine and Metabolic Diseases (R21)

Program Announcement (PA) Number: PA-09-133

Opening Date: May 16, 2009  
Letters of Intent Receipt Date(s): N/A  
Application Receipt/Submission Date(s): Multiple dates  
Expiration Date: May 8, 2012  
<http://grants.nih.gov/grants/guide/pa-files/PA-09-133.html>

Purpose: This FOA, issued by National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the Office of Dietary Supplements (ODS) of the National Institutes of Health, encourages exploratory/developmental clinical research related to the prevention or treatment of diabetes, obesity and endocrine and genetic metabolic diseases. The Pilot and Feasibility Clinical Research Grants Program is designed to allow initiation of exploratory, short-term clinical studies, so that new ideas may be investigated without stringent requirements for preliminary data. The short-term studies should focus on research questions that are likely to have high clinical impact. They can include testing a new prevention strategy, a new intervention, or unique combinations of therapies. A high priority is the use of such studies to help stimulate the translation of promising research developments from the laboratory into clinical practice in diabetes, endocrine diseases and genetic metabolic diseases, including cystic fibrosis.

### Innovative Therapies and Tools for Screenable Disorders in Newborns (R01)

Program Announcement (PA) Number: PAR-10-230

Opening Date: September 5, 2010  
Letters of Intent Receipt Date: 30 days prior to application due date  
Application Due Date: See <http://grants1.nih.gov/grants/funding/submissionschedule.htm>  
Expiration Date: September 8, 2013  
<http://grants.nih.gov/grants/guide/pa-files/PAR-10-230.html>

Purpose: This FOA, issued by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Institute of Diabetes and Digestive and Kidney Disease, the National Institute of Neurological Disorders and Stroke, and the National Institute on Deafness and Other Communication Disorders encourages Research Project Grant applications from institutions/ organizations that propose research relevant to the basic understanding and development of therapeutic interventions for currently screened conditions and “high priority” genetic conditions for which screening could be possible in the near future. In this FOA, a “high priority” condition is one for which the development of an efficacious therapy would make the condition amenable to newborn screening.

## American Society of Hematology

### Patient Group Research Grant Opportunities

To draw together the multitude of hematology-related research grant opportunities that are available through patient groups, the Society has created a section on the ASH Web site that simplifies your search for requests for blood and blood disease research topics. (<http://www.hematology.org/Research/2874.aspx>)

## Children’s Cardiomyopathy Foundation

The Children’s Cardiomyopathy Foundation (CCF) offers two annual grant programs to support innovative basic, clinical, population, or translational studies relevant to the cause, diagnosis, or treatment of cardiomyopathy (Dilated, Hypertrophic, Restrictive, Left Ventricular Non-Compaction, or Arrhythmogenic Right Ventricular Cardiomyopathy) in children under the age of 18 years. The goal of CCF’s grant programs is to advance medical knowledge of the basic mechanism of the disease and to develop more accurate diagnostic methods and improved therapies for children affected by cardiomyopathy. (<http://www.childrenscardiomyopathy.org/site/grants.php>)

## United Mitochondrial Disease Foundation

The United Mitochondrial Disease Foundation (UMDF) Research Grant Program began in 1997 out of a desire to fund research toward diagnoses, treatments, and cures for mitochondrial disease. ([http://www.umdf.org/site/c.dnJEKLNqFoG/b.3790285/k.6CE6/Research\\_Grant\\_Program.htm](http://www.umdf.org/site/c.dnJEKLNqFoG/b.3790285/k.6CE6/Research_Grant_Program.htm))



# Barth Syndrome Trust

## Celebrate Each Life

By Michaela Damin, Chair, Barth Syndrome Trust (UK & Europe)



Nicholas and Dillon ... seeing eye to eye!  
(Photo courtesy of BStrust ~ 2011.)

This is a group where everyone participates in some way.

Affected families make donations to the Trust, do fundraising, volunteer their time and support the services we provide. Through their example, they inspire their friends, wider family and their colleagues to support our vital work.

Furthermore, we are fortunate to have access to quality care from the medical professionals looking after our boys and men.

Lastly, we have the strength that comes from working together.

Let us celebrate each life, every person's individual contribution, as well as the special group which is the Barth Syndrome community.

In these pages, you'll read about one little boy's heroic struggle- a little boy who decided that actually he had quite "a bit more living to do." You'll also read about two French families who met each other for the first time at the clinic in the UK. The Physiotherapy and Occupational therapy team from Bristol report back on lessons learned from seeing an increased number of patients. This in turn translates into practical assistance for the families.

We've included a summary of fundraising activities but, for those wishing to read more, we've created a special insert where we can properly sing the praises of all those special people who have raised much needed funds to allow us to continue with our important work. Thank you all.

### Highlights of 2011 so far:

- On-going success of NHS Service and Clinic, offering expert advice right from diagnosis.
- Family Days for affected families – a chance to meet, talk and (for the children at least!) play together outside of the hospital setting.
- Providing assistance to families with travel costs so that they are able to travel across the UK and Europe to attend specialist clinics.
- On-going funding of research – in 2010 we funded Professor Greenberg's research into Barth syndrome "Perturbation of mitophagy in cardiolipin mutants." Project cost: \$40,000
- In 2011, we are funding Dr. Anton I. De Kroon's research into "The preferred acyl chain donor of *Taz1p* in the acylation of monolysocardiolipin. Project cost: \$40 000.



Suzy Green in discussion with Dr. Colin Steward at Family Gathering.



Boys at the March Family Gathering. (Photos courtesy of BStrust ~ 2011.)

# NHS Barth Syndrome Clinic March 2011

## Physio and Occupational Therapists' Report

By Ann-Marie Apa (Senior Paediatric Occupational Therapist) and Hannah Harbidge (Senior Paediatric Physiotherapist),  
Bristol Royal Hospital for Children



Ieuan during PT evaluation with Hannah at NHS Bristol Clinic.

In the presentation of Barth syndrome, the following observations have been made in relation to specific physical weaknesses. These include:

1. Decreased upper body strength including difficulty with fine motor skill development
2. Decreased hip strength making running slow and inefficient and making it difficult to get up from the floor
3. Decreased trunk / core strength resulting in poor posture and sitting tolerance
4. Limited endurance / generalised fatigue

This year (March 2011) in the Barth Clinic run by Dr. Steward at the Bristol Royal Hospital for Children, the adolescent boys who attended were given the option to be assessed by a paediatric physiotherapist and occupational therapist.

Standardised assessments for physical function, based on the North Star Assessment, looked at proximal muscle weakness and timed functional activities. The Biometrics E-link programme was used to record baseline grip strength and variations in pinch grip strength.

Handwriting samples were taken and advice provided to children and their families on how to promote a good sitting posture and an efficient/mature pencil grasp. Yellow and green theraputty was provided to each child as well as detailed exercise sheets to help maintain and challenge overall hand strength. The boys were quite motivated by this stretchy, resistive material!

Our future aim is to assess all of the boys who come to the clinic to increase our knowledge of the condition and to determine whether the areas we assess change significantly as the boys grow and mature. The information we gain from these assessments will allow us to offer specific advice to new and returning children who attend the clinic.

### **NHS\* Barth Syndrome Clinic**

**Thursday 29<sup>th</sup> - Friday 30<sup>th</sup> September 2011**

Bristol Royal Hospital for Children  
*The centre of expertise for Barth syndrome*

Families from Europe must have a completed S2 form (previously E112)

**followed by**

### **Barth Syndrome Trust Family Day in Bristol**

**Saturday 1<sup>st</sup> October 2011**

To register, please contact Barth Syndrome Trust at [info@barthsyndrome.org.uk](mailto:info@barthsyndrome.org.uk)  
or

Debbie Riddiford at [barthsyndromeservice@uhbristol.nhs.uk](mailto:barthsyndromeservice@uhbristol.nhs.uk)

\*National Health Service (NHS)

\*\*Photos on pages 22 and 23 are courtesy of the Barth Syndrome Service.

# French Families at the Bristol Barth Syndrome Clinic

## Holistic Approach to Barth Syndrome

By Florence Mannes, Chair, Association Barth France



Florence and Raphaël at NHS Bristol Clinic.  
(Photo courtesy of Barth Syndrome Service ~ 2011.)

It was a long journey, and a long day...but it was worth it a thousand times! During those three days spent in Bristol, we learnt so much, in three different fields:

- Research / medical aspects of Barth syndrome;
- Medical follow up for Raphaël;
- Human relations!!!

During the introduction by Dr. Colin Steward, it was great to hear about so many different doctors working on Barth syndrome. We know that, thanks to the Barth Syndrome Foundation, Barth Syndrome Trust, Barth Syndrome Foundation of Canada, Barth Trust South Africa, and Barth France, many doctors are working to find a cure for our boys...but it "becomes real" when you meet them. They work in many different fields, and you can tell, listening to them, that they love what they do, and that they are dedicated to making progress for our boys.

During the different medical interviews we had at the clinic, we were able to discuss our son's health with doctors who KNEW Barth syndrome and who had already met "many" other Barth boys. Except for the clinics held in Florida last July, it was the first time we could talk to doctors who know more about Barth Syndrome than we do. Additionally, they really took the time to get to know our son Raphaël, to understand what was going well and where there were problems. Knowing that we will be able to meet these doctors again in one year is a real relief for us. Instead of treating Raphaël's neutropenia or cardiomyopathy separately, the doctors here are treating the disease as a whole.

Bristol does not mean only clinics, but also social gatherings. On the two evenings we spent in Bristol, but also on the Saturday after the clinic, we were able to meet many families we knew only by name (via the Listserv), spend time with families we met in Florida, and meet new families. Sharing experiences with people who know what we are going through is always special, and we can find that only during the BST/BSF socials. Additionally, it was the first time we had met another French family. Being able to communicate in our native language is also important. It was a great experience for us.

To make short a long story: we definitely hope to be able to be in Bristol next March!



Barth Syndrome Trust Family Day after the Clinic - March 2011. (Photo courtesy of BStTrust ~ 2011.)

(Cont'd from page 24)



Pierre fête le 5ème anniversaire de son nouveau coeur.

## Rencontrez Pierre

*Par Christine et Benoit, les parents d'un fils diagnostiqué en France*

Nous sommes les parents de 3 enfants, Manon 11 ans, Quentin 8 ans et Pierre 6 ans. C'est notre petit dernier qui est atteint du syndrome de Barth. Il a été diagnostiqué à 3 ans après de nombreux problèmes cardiaques, de croissance, d'alimentation et de neutropénies.

Pierre a été greffé à l'âge de 8 mois dans un hôpital à Lyon, après avoir passé 15 jours sur la Berlin Heart. Il est toujours suivi par sa cardiologue tous les deux mois et par un hématologue sur St Etienne où nous habitons.

Nous avons participé pour la première fois cette année à la Barth Clinic à Bristol, ce qui nous a apporté de nombreux renseignements sur la maladie et la conduite à tenir. Les professionnels de santé de la Barth Clinic ont été vraiment à l'écoute et très disponibles pour nous, cela nous a permis aussi de rencontrer d'autres familles dans le même cas que nous. Nous nous sentons moins seuls face à cette maladie si rare. Ces moments nous ont été très agréables et nous espérons pouvoir nous retrouver prochainement.

*\*Ci-dessous, la traduction anglaise de cet article par Annick Manton.*



Pierre during cardiac evaluation at NHS Bristol Clinic.  
(Photo courtesy of the Barth Syndrome Service ~ 2011.)

## Meet Pierre

*By Chris and Benoit, Parents of Diagnosed Son, France*

We have three children, Manon, aged 11, Quentin aged 8 and Pierre, aged 6. Our youngest son, Pierre, has Barth syndrome. He was diagnosed with the disease at 3 years old after having had many problems relating to his cardiac function, growth, feeding, and neutropenia.

Pierre had a heart transplant at the age of 8 months in a hospital in Lyon after he spent 15 days on a Berlin heart. He sees his cardiologist every two months and also sees a hematologist in St Etienne, where we live.

This year, for the first time we participated in the Barth Clinic in Bristol where we gathered a wealth of information about the syndrome and learned how to manage it. The health professionals were very accessible and gave us their undivided attention. The clinic also allowed us to meet other families in the same situation as us. We feel less isolated in the face of this rare illness. We spent some very pleasant moments together and hope to be able to meet again at the next one.

*\*The English translation of this article has been provided by Annick Manton, Volunteer Translator.*

*\*The French translation of this article, provided by Chris and Benoit, is featured above.*

## A Big Thank You

Since autumn 2010, fundraising throughout the UK and beyond has brought in a steady flow of funds: raffles and runs, cooking, coffee mornings and quizzes, bacon butty and book sales, tennis and teas. In addition, we have had many donations from across our region, Europe and UK. It is with sadness and gratitude that we have received funds in memory of beloved sons. Every contribution is important and much appreciated. Your generosity ensures that we are able to continue with all our programmes. (See funding of research in Utrecht on page 9.)



# Joe and His "Bertie the Bus Berlin Heart"

*By Rachel, Mother of Diagnosed Son, Age 2, United Kingdom*



Joe, Teddy and Bertie — Ready to Roll!  
*(Photo courtesy of Rachel ~ 2011.)*

Joe was born on 20<sup>th</sup> October 2008. He was diagnosed with cardiomyopathy at three weeks old and with Barth syndrome at 15 weeks. He suffered heart failure as a baby, was stabilised on heart medications and came home in April 2009. Until January 2011, we had a happy, bouncy little boy who had good heart function and was generally very well.

A scan in December 2010 showed that his heart valves were leaking but he seemed well. However on 25<sup>th</sup> January, he suddenly vomited and turned grey and we rushed him to our local hospital. He was transferred to London where a scan showed that he was back in heart failure and both his ventricles were failing. He was put on IV inotropes and was listed for a heart transplant on 4<sup>th</sup> February 2011.

Joe was fairly much okay until a Saturday three weeks later when events changed our lives forever. Up to this point, I had always believed that Joe would recover as he had done when he was a baby. As we got Joe ready for bed, his eyes rolled and he suddenly

fell backwards. The heart monitor showed he was in ventricular fibrillation, and it was the start of a nightmare. Overall he was resuscitated seven times, with two arrests lasting over 18 minutes. Twice the doctor considered stopping the resuscitation, and twice Joe decided that actually he had a bit more living to do.

The decision was made to transfer him to Great Ormond Street Hospital in London for ECMO (Extra Corporeal Membrane Oxygenation). An ECMO machine is like a heart-lung bypass machine which takes over the work of the heart and lungs for a while, allowing them to rest. We arrived at Great Ormond Street after 10pm, and Joe was on ECMO by 1am the following morning. At some point that night, after only being on ECMO a few hours, he was shaking his head at the nurse who wanted to join him in his warm bed. By dawn, he was in elbow splints as he is hard to sedate and he wanted to pull all his tubes out.

On the Monday, 36 hours after starting on ECMO, "Bertie the Berlin Heart" came into our lives, and he has become a good friend. Berlins do tend to get names apparently, so "Bertie the Bus" he became. Three days later, while still ventilated, he was mouthing along to the story of the Hungry Caterpillar. That's when we knew he had come through all the resuscitation with little or no neurological damage.

The Berlin heart has two parts to it: the driving unit which is much like a 150kg shopping trolley containing three pneumatic pumps and a computer that controls the rate and force with which it pumps. Joe has support for two chambers: a Left Ventricular Assist Device and a Right Ventricular Assist Device implanted into his heart to support his heart as a bridge to transplant while we wait for a donor heart. Joe's chambers are attached to the driving unit with two long hoses. Seeing blood whoosh through the chambers that hang between his knees took some getting used to!

The Berlin Heart gives Joe an amazing quality of life. He can play, walk and annoy his older sister; all those toddler things that two year boys should be doing. We can go off the ward for coffee with him, and go to the hospital play centre where he gets very messy and enjoys joining in with all the activities.

We have now been a "Berlin Family" for nearly 13 weeks. We uprooted our lives from the east coast of England in Kent to Great Ormond Street Hospital in London. Joe's sister is attending the school here at the hospital, and his Daddy commutes to work from our accommodation.

For us, much of the support we have had over the last few months has come from our BSF/BST friends. Their understanding and regular listening ears have been amazing...

I can't end Joe's story here. Today, the 28<sup>th</sup> May marks his 90<sup>th</sup> day on the Berlin heart. The longest time a child has been on a Berlin heart at Great Ormond Street Hospital is 227 days, so Joe may still have a long wait ahead of him.

# Barth Syndrome Foundation of Canada

## The Canadian President's Report — Spring 2011

By Lynn Elwood, President, Barth Syndrome Foundation of Canada



Lynn, and her son Adam (age20) at BSF's 2010 Conference.  
(Photo courtesy of Amanda Clark ~ 2010.)

Looking back on the last year with the Barth Syndrome Foundation of Canada I'm struck by the depth of leadership we have achieved. In a volunteer organization there are times when individuals are not available to do the jobs they are expected to do. Our team of volunteers is now so strong that when someone is not available to do their job, someone else steps in and makes sure the work gets done. As a result of these committed volunteers we have made great progress this year despite all the extra work connected to BSF's 2010 Conference.

We have begun to deliver our new vision Enhancing the lives and outcomes of Canadian individuals and families affected by Barth syndrome and have had a Needs Assessment done to better assist the affected individuals within Canada. We received some great insights from the preliminary report and have begun to make changes based on it. We await the final report within the next month or so. One of the things that we were asked is to stop calling our affected population "Barth boys." As was pointed out, they certainly don't always want to be called "boys" as they grow older. You will hear us now calling them "affected individuals" or "men and boys affected by Barth syndrome." This may sound a little clinical, but it is more acceptable to everyone.

Our finances remain strong, with approximately a year's worth of operating budget in reserve so that we can complete our programs even in challenging economic times. We have been conservative in our budgeting and have been successful in exceeding targets for fundraising as you will see from the article in this newsletter. We did choose to spend in excess of our revenue in 2010 and this was a deliberate choice by our board. As a charity organization, our aim is to use funds to meet our program goals, not to save a large amount. We were met with the option of fully funding a Canadian grant that we and the Scientific and Medical Advisory Board of the BSF felt could benefit our cause. This grant, "The role of human monolysocardiolipin acyltransferase in Barth syndrome," submitted by Grant M. Hatch PhD, University of Manitoba, was fully funded in 2010 and our finances have remained strong enough that we have fully funded a grant in 2011.

In 2011 we have funded a grant entitled, "A screen for drug leads for the treatment of Barth syndrome," submitted by Christopher R. McMaster, PhD, Professor of Pediatrics and Biochemistry, Dalhousie University. We are very excited about this grant as is the board of the Barth Syndrome Foundation and Matt Toth, PhD, the BSF Science Director who oversees the international grant program. It is a critical step in researching possible medication options for Barth syndrome. This type of testing is often cost prohibitive for small organizations to undertake, but Dr. McMaster has been able to secure help such that the cost to our organization is modest and within our grant guidelines. This is a very positive step along the way to achieving treatment guidelines for Barth syndrome and we are looking forward to the findings from this research.

The 2011 year has started out well, with plans for another golf tournament at an exciting new location, some private fundraisers and endless enthusiasm. We recently held our Annual General meeting and re-elected our President, Lynn Elwood and Treasurer, Chris Hope, and we used this meeting as a chance to have a family outreach gathering. We had a great time bowling and sharing some laughter with 31 family members and affected individuals. We are looking forward to planning another gathering later in the year as these events are one of the things our affected boys and men really appreciate. Look to our updated website [www.barthsyndrome.ca](http://www.barthsyndrome.ca) for news updates throughout the year.

# BSFCa Contributions to BSF's 2010 International Conference

*By Lynn Elwood, President, Barth Syndrome Foundation of Canada*

Every two years, the physicians, researchers and families associated with Barth syndrome internationally come together at a conference, the most recent held in 2010 in Orlando, Florida. It is an amazing, professional conference hosted by BSF, Inc., and attended by 400 people from all over the world. Fourteen Canadians attended in 2010 representing four of the eight known families in our country.



Shelley Bowen with a number of the older Barth guys at BSF's 2010 Conference.  
*(Photo courtesy of Cherie Schrader ~ 2010.)*

The last two-year period has been marked with the loss of some of the older and well known men as well as some younger boys affected by Barth syndrome, so there were some bitter-sweet moments during the Conference. Our affected young men showed us that we need to openly celebrate the lives of those that have been lost, and both the affected individuals and the families benefited from some professional advice on dealing with this.

The physicians and scientists brought families news of advances and were able to provide some specific advice based on findings from previous conferences and their research. We learned about some diet options that may help our affected individuals, got some exercise advice, and learned more about the cardiac aspects of the condition. The science panel did a great job of putting the research grant updates into understandable terms so that we could share in the excitement of the work that is being done.

We joined the scientific and medical poster session that was sponsored by BSF of Canada and were able to meet with the scientists whose research grants we have funded over the past years. We had some great interaction with them and support from a number of the researchers who offered to participate in presentations to physician communities in their regions.

The research and advances made during one week at the Conference were significant as nearly 40 affected individuals participated in the clinics and new research was begun. As exciting as all of this was, as a parent, the strongest benefit for me was in seeing my son laughing, playing and talking earnestly with his true peers, being able to relax and share experiences with others who truly understand what he faces daily. The benefits, both scientifically and socially from this one week Conference will be felt for a long time to come.

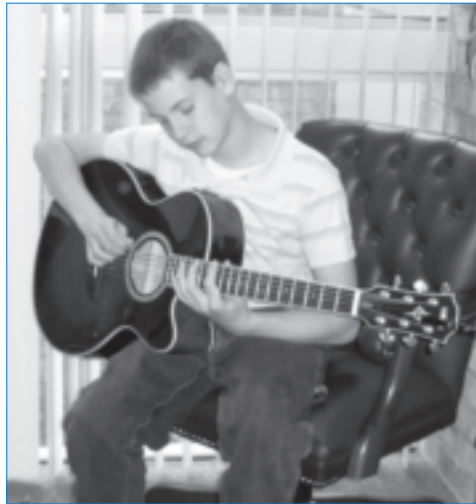


BSFCa co-sponsored the Poster Session at BSF's 2010 Conference.  
*(Photo courtesy of BSFCa ~ 2010.)*

# Growing Up With Barth Syndrome

## A Talk With Travis

By Lynn Elwood, President, Barth Syndrome Foundation of Canada



Travis enjoys his guitar! (Photo courtesy of BSCa.)

In many ways a typical 16-year old, Travis was patient with being asked about the challenges and issues he faces as he grows up with Barth syndrome. Travis is now in grade 9 and has moved this year from a public school to high school environment. Here are some things we talked about that affect him:

**What are some of the challenges in going to High School?** It isn't all that different from public school, but I get more freedom to pick my courses. I chose Computer Technology. I'm pretty good with computers.

**Do you have extra help?** I don't have anyone in classes with me and there is no special treatment in class, but there is a room where I can go to get help when I need it. I get extra time on tests when I need it. I decide when I need help and ask.

**How do your teachers know about Barth syndrome?** I give the teachers a pamphlet on Barth syndrome so they know about it.

**What do you like to do outside of school?** I like to swim and hang with friends and I like to play guitar. I take lessons once a week and I play the guitar every day. I like most songs and one of my favourites is Jimmy Hendrix.

Travis has played his guitar at a fund-raising musical a few years ago and at some of the family gatherings we have had. At our recent AGM he played for some of the younger children who were there and it is clear that he is very gifted and getting better with each passing year. Thank you for the talk and for the music, Travis!

## Raising Green Through Grassroots Fundraising

By Cathy Ritter, Vice President, Barth Syndrome Foundation of Canada

Like many other charitable organizations, the Barth Syndrome Foundation of Canada (BSFCa) relies on grassroots fundraising to raise funds to further its programs, goals and mission. The past year provided a bumper crop of events which enabled us to continue our work.

Thank you to all of the wonderful volunteers and supporters who helped plan, promote or support one of these events. You not only helped "raise some green" but also increase awareness about Barth syndrome while spreading the word about BSFCa. Feel free to contact us about any fundraising event you wish to do. Here is to another successful year in 2011!



George Olliver and the Barquettes! (Photo courtesy of BSCa ~ 2010.)

### Boogie for Barth!

After last years successful dance and silent auction where they raised \$5000.00 for the Barth Syndrome Foundation of Canada, Bob and Susan McJannett felt that this should be an annual event. So they are going to do it again!

The date chosen will be Saturday October 1, 2011. Once again it will be held at the Toronto Humber Yacht Club. At last years dance we were treated to a great evening's entertainment from George Olliver, "the blue eyed prince of soul," and guitar virtuoso Bob McAlpine.

(Cont'd on page 30)



(Cont'd from page 29)

In order to top 2010 we are bringing back George with his four piece band and we have changed the date to October 1<sup>st</sup> so many of the cottage folk could join us. As we did last year we will also hold a silent auction with all the income being donated to Barth Syndrome Foundation of Canada. A vast array of items have already been donated. In fact we hope to come up with another welder! We are still looking for interesting items to add to our auction. No one ever wants to look back; our goal is to exceed 2010, so we can move closer to finding a cure. The number of tickets sold is always limited and we promise a fun evening supporting a very worthy cause!



### Blue Christmas

*By Susan Hone, Secretary, Barth Syndrome Foundation of Canada*

A few years ago, BSFCa received a donation of thousands of temporary tattoos. I kept looking at these tattoos and wondering what else they would be able to be used on. As I was decorating for Christmas, I looked at some painted ornaments I had made and decided the tattoos would look good on ornaments. I made a few for family, friends and the BSFCa executive and then thought I would go a little further and try to make some money for BSFCa from these ornaments. I took them to the 2010 International Conference and was thrilled when they all sold and I made over \$100.00 for BSFCa.



### Christmas Raffle

Several martial arts dojos (communities) gathered together to raise money for BSFCa this past fall. Steve Kubien, one of the members runs his own woodworking company, Green Leaf Wood Studios, and was very enthusiastic when Lynn and Paula approached him with the Christmas raffle idea. In the end, we chose a beautiful peppermill made of curly maple dyed a vibrant burgundy colour and a roller ball pen made out of a Southeast Asian amboynas burl. The prizes were very well received and \$395.00 was raised for BSFCa.



## Canadian Volunteers take Barth Worldwide

*By Les Morris, BSFCa Volunteer; Team Member, BSF Publications Team*



*Helen Hope at Little Hearts Hospital, Calcutta, India.  
(Photo courtesy of Helen Hope.)*

Helen and Harry Hope are Barth grandparents. They have been ardent supporters of our Canadian organization since its beginning. Not only do they contribute in many ways here in Canada but they spread awareness of Barth syndrome wherever they go.

They travel extensively by taking advantage of excursions organized by the Rotary Club of which they are members. At our AGM this year they outlined for us their trip to India which highlighted the good work done by the "Little Hearts Hospital" in Calcutta. More than 80,000 children in India have congenital heart defects that require medical intervention but only 8,000 to 10,000 are treated each year. Canadian Rotarians, in cooperation with heart surgeons, hospitals and Rotarians in India, are changing these statistics. Rotary Grants and contributions support this small operation which 'helps children lead better lives,' an aim which closely parallels our efforts for affected individuals with Barth syndrome.

Our special thanks goes out to these seasoned travelers and Barth grandparents who work so hard to support the Canadian organization and spread the word around the world.

# The Origins of Barth France

By Florence Mannes, Chair, Association Barth France



Florence and her son, Raphaël, age 2  
(Photo courtesy of Amanda Clark ~ 2010.)

In August 2009, when our son was first diagnosed with Barth syndrome, Philippe and I felt stunned and powerless. We didn't know the first thing about this disease and, perhaps most upsetting, we had no idea how to help our son.

The first step was to educate ourselves. We contacted the Barth Syndrome Foundation and the Barth Syndrome Trust and began to communicate with the network of fellow parents of Barth boys, and to learn everything we could about this disease and its treatments. Yet as we became further immersed in this community of families, doctors, and researchers, we felt compelled to mobilize, to direct more of our energy and lives towards supporting this very personal cause. Fate had given us a new purpose: to do whatever possible to help our son and all the children touched by this illness, those whom we met at the Barth Syndrome Foundation (BSF) Conference in July 2010, those whom we knew only through their shared experiences on the listserv, and those who have yet to be diagnosed.

It was at BSF's 2010 Conference that our ambitions began to take shape. We met so many people who volunteered their time and energy in support of BSF that our next step became clear to us: why not create a French branch of BSF, to build a support and education network for those families touched by Barth syndrome in France and Europe?

Another element took shape: Philippe had just committed to participating in the Ironman of Nice triathlon and, inspired by Gary Rodbell's 2010 conference presentation about his fundraising and awareness success associated with Ironman races in the US, would run under the Barth banner.

In September 2010, we registered Barth France as a non-profit, public-service organization (a distinction which allows donors to benefit from a 67% tax reduction on gifts), with a three-pronged mission:

- To support Barth patients and their families in France, in particular by providing French translations of literature, research, and news related to Barth syndrome, and in helping them utilize the support systems provided by the Barth Syndrome Foundation and the Barth Syndrome Trust;
- To heighten visibility of Barth syndrome both in medical circles and the public in order to encourage screenings and early detection;
- To raise funds in support of BSF's research projects.

Since its inception, Barth France has endeavored to publicize this disease and gain support through several channels: the creation of the website [www.barthfrance.com](http://www.barthfrance.com), publishing of informational pamphlets, and partnerships with several businesses (Domaine de la Bretesche, Lucky Staff, Genae, Lookingo, Mannespieces...). We are especially grateful for the support of Suez Lyonnaise des Eaux, a premier French company and principal sponsor of France's five triathlons involving over 5,000 participants. At each race, Barth France will be proudly represented in the "course village," distributing information and selling official race t-shirts bearing the Barth logo. We will also be selling hats, swim caps, triathlon suits, all with our logo and website address. Our partnering sponsors have generously provided these products for sale in support of Barth France; all merchandise is also available through the Barth France website.

In addition, Barth France has actively been seeking financing for the creation, publishing, and dissemination of informational packets on Barth syndrome to increase awareness among cardiologists, pediatricians, and other medical professionals.

Finally, with the aid of Annick Manton and Madeleine Lallemand, [barthfrance.com](http://barthfrance.com) has begun to display French translations of essential documents published by the Barth Syndrome Foundation.

The primary goals of Barth France for the coming months are as follows:

- To heighten visibility of Barth syndrome and bolster its web presence on relevant sites (medical and rare disease resources/forums, etc.);
- To increase awareness of Barth syndrome among medical professionals;
- To collect donations through the support networks of participants in sporting events: marathons, triathlons, and a golf competition to be held in Brittany, France on July 31;
- To continue translating essential documents and articles published by BSF for a French-speaking audience.

\*See page 32 for the French translation of this article.

# La naissance de l'association Barth France

By Florence Mannes, Présidente de l'association Barth France



En aout 2009, lorsque le diagnostic du Syndrome de Barth est tombé, Philippe et moi nous sommes sentis impuissants. Nous ne connaissions rien de cette maladie, et nous ne savions pas comment aider notre fils. Alors nous avons pris contact avec la Barth Syndrome Foundation et la Barth Syndrome Trust : communiquer avec d'autres parents, prendre connaissance des nombreuses informations mises à notre dispositions était essentiel, mais cependant pas suffisant à nos yeux : nous voulions faire plus, avoir la sensation de « servir à quelque chose » au sein de cette communauté, pour notre fils et pour tous les enfants atteints, ceux que nous avons pu rencontrer à la conférence tenue en Floride en juillet 2010, ceux dont nous lisions les noms sur la listserv, mais aussi tous ceux, nombreux, qui n'ont pas la chance d'avoir un diagnostic.

C'est lors de la conférence de Floride que les choses sont devenues plus concrètes : nous avons rencontré tellement de bénévoles qui s'impliquaient dans la BSF que l'idée de cette démarche est venue à nous : pourquoi pas ne pas créer une branche française de la BSF?

En parallèle, Philippe avait décidé de courir l'Ironman de Nice, et, suite à la présentation de Gary Rodbell lors de la Conférence tenue en Floride en juillet 2010 sur la participation aux USA de Team Will à des Ironman pour faire connaître le syndrome de Barth, et collecter des fonds, l'idée qu'il puisse courir pour Barth, ajoutait à ce défi une nouvelle perspective.

A notre retour en France, en septembre 2010, nous avons donc créé Barth France, association loi 1901, reconnue d'utilité public (aspect essentiel, puisque cela permet aux donateurs de bénéficier d'une réduction fiscale de 67% du montant de leur don), avec trois buts essentiels:

- Soutenir les familles francophones atteintes, en particulier en mettant à leur disposition la traduction française des informations communiquées par la BSF, et en faisant le lien entre ces familles et la BSF / BST lorsque cela s'avère nécessaire;
- faire connaître le Syndrome de Barth, auprès de la communauté médicale française mais aussi du grand public, pour favoriser le dépistage;
- récolter des fonds, pour soutenir la recherche, via le programme de recherche de la BSF.

Depuis sa création, l'essentiel de la démarche de l'association Barth France a été de se faire connaître, via, par exemple, la création d'un site internet ([www.barthfrance.com](http://www.barthfrance.com)), la création de supports de communication (plaquette et dépliant d'information), la mise en place de partenariats avec différentes entreprises (Domaine de la Bretesche, Lucky Staff, Genae, Lookingo, Mannes,...), et surtout, un accord avec Suez Lyonnaise des Eaux, une des principales entreprises françaises, et premier sponsor de la fédération française de triathlon, qui organise 5 triathlon, comptant au total plus de 5000 participants. A l'occasion de ces épreuves, Barth France est présent sur le village de la course, distribue des dépliants d'information, et participe à la vente des 2.500 tee-shirts officiel du Grand Prix Lyonnaise des Eaux de Triathlon, vendus au profit de Barth France, et portant le logo de Barth et l'adresse du site internet.

Lors de ces 5 triathlon, Barth France vend également des casquettes, bonnets de bain, combinaisons de triathlons (portant, toujours, le logo de Barth et l'adresse du site internet). L'achat de ces produits a été financé par des entreprises partenaires. Ces produits sont également disponibles sur le site internet, et ont déjà fait l'objet d'un certain nombre de commandes.

Par ailleurs, Barth France a également déposé des dossiers auprès de différentes fondations, dans le but d'obtenir le financement de la réalisation, l'édition et l'envoi de livrets d'information sur le Syndrome de Barth, pour sensibiliser les cardiologues et les pédiatres à cette maladie.

Enfin, Avec l'aide d'Annick Manton et de Madeleine Lallemand, Barth France a commencé à mettre en ligne sur son site internet certaines traductions françaises des fiches pratiques rédigées par la BSF.

Au cours des prochains mois, Barth France s'est fixé les objectifs suivants:

- Renforcer la visibilité du Syndrome de Barth sur les sites internet dédiés (médicaux, maladies rares, ...);
- Faire connaître au milieu médical (CHU, cardiologues, pédiatres) le Syndrome de Barth (avec ou sans le support d'une Fondation);
- Favoriser la collecte de fonds, via la participation de coureurs à des épreuves sportives (marathon, triathlon) sous les couleurs de Barth France, et via l'organisation d'une compétition de golf (31/07);
- Poursuivre la traduction française des «fiches pratiques » et des livrets d'information rédigés par BSF.

*\*Voir page 31 pour la traduction anglaise de cet article.*

# Ironman4Barth runs the Nice Ironman

They've talked about doing it for the last 20 years...and in just a few weeks, they will finally take their places at the starting line of the Ironman of Nice (3.8 km of swimming, 180 km of biking, and 42 km on foot\*). What differentiates the participants of Team Barth France from their fellow athletes is their double challenge of completing the course and raising funds for boys afflicted with Barth syndrome.

A donation site (<http://1barthfrance.alvarum.net/ironman4barth-nice>) has been created for the six team members to solicit support donations from family, friends, co-workers, and others. To date, 7,000 euros have been collected in this effort. Some businesses have been solicited for funds and are expected to give as well.

The six participants (Philippe Mannes, Pierre Mannes, Arnaud Delaunay, Dimitri Buytaert, Marc Pillot, and Paul Van der Weiden) will all run as Barth representatives (their uniforms are the same as those worn by Team Will) and hope that their efforts will prove beneficial to this important shared cause. Team Barth France would like to thank Team Will and especially Gary, for being so inspiring.

*\*See page 34 for the French translation of this article.*



(L-R) Team members Xavier Brunschvicg, Aurélie Duez, Paul Van der Weiden, Marc Pillot, Philippe Mannes, and Arnaud Delaunay. (Photo courtesy of Barth France.)

## My Son, My Ironman

*By Philippe Mannes, Father of Diagnosed Son; Trustee, Association Barth France; Member of Team Barth France*

**I've found my motivation to participate. I'll need that motivation... to carry me to the finish line.**

Each Ironman and Ironwoman experiences the initial thrill of signing up for their first triathlon, of committing themselves to an ordeal that, to the average person, might seem a little bit insane. I myself had dreamt of it for a long time, first inspired by my childhood tennis instructor Eric Plantin, a 25-year triathlon participant who had finished 12th in the famous Hawaii Ironman. I became an avid fan, watching and studying each race...and of course, being a kid, I dreamt of following in these impressive athletes' footsteps. One does not dream of the triathlon as one might dream of other

sports. There is no triumphant lifting of a golden trophy for a million spectators and, no stadium full of screaming fans. The dream is quite simply to endure the test and finally to pass the finish line, crawling if necessary, vindicated by the cry, "You are an Ironman!"

Yet we all know too well that, in practice, this dream can more closely resemble a nightmare. Exhausted after swimming and cycling through the first two-thirds of the race, with an entire running marathon still remaining, it takes a special kind of motivation to push on.

Each triathlete finds his or her motivating force in a different place. It could lie in the image of a faraway destination, in the arms of one's beloved, in the encouragement of friends...or in the eyes of a child. I have a young son afflicted by a complex condition called Barth syndrome. He will never run a triathlon; his body would not allow it. He is just two years old now and doesn't understand his physical limitations. He doesn't know that he won't be able to follow in the footsteps of his Papa...and yet his Papa runs for both of them, because it is in the eyes of his small son that he finds his motivation.

In a way, the triathlete is a selfish character. He runs for himself, for his own sense of achievement rather than for his team or country. Yet to push through those last, most painful kilometers and make it to the finish line, he must call for help outside himself. In an Ironman competition, every single participant suffers, from the first to the last finisher. It isn't easy for anyone, and so everyone must find his or her strength to keep going. This is the most meaningful and powerful motivation that I can find to bring me to the finish line, and it would be an honor to share that motivation with others...and to show my small son the great strength he brings to Papa and his friends.

On June 26, at the Ironman of Nice, a highly motivated team will run in support of a little boy whose small body achieves miracles each day, making him a true Ironman in my eyes. Even if your own life is overflowing with motivational forces already, I offer one last plea: the eyes of a child thank you and hope that your support will allow the doctors to find remedies for his condition. Please share your strength with him...and let him share a bit of his strength with you.

*\*See page 34 for the French translation of this article.*



# Ironman4Barth — l'Ironman de Nice – 26 juin 2011

Ils en ont parlé pendant 20 ans...et dans quelques semaines, ils prendront le départ de l'Ironman de Nice (3,8 km de natation, 180 km de vélo et 42 km à pied)...mais à la différence d'autres coureurs, pour les coureurs de Barth France (l'équipe Ironman4Barth) le défi est double : finir l'Ironman et récolter des fonds pour les enfants atteints du Syndrome de Barth.

Une page de collecte (<http://i1barthfrance.alvarum.net/ironman4barth-nice>) permet aux 6 coureurs de l'équipe de solliciter les familles, amis, proches pour les soutenir dans cet effort. A ce jour, 7.000 euros ont été collectés. Des entreprises ont également été contactées, et devraient également participer à cette opération.

Ils courent tous sous les couleurs de Barth (les maillots sont les mêmes que ceux portés par Team Will), et espèrent également favoriser la connaissance du Syndrome de Barth. Merci à Team Will et particulièrement à Gary pour son inspiration.

\* Voir page 33 pour la traduction anglaise de cet article.



## Mon Fils, Mon Ironman

*By Philippe Mannes, papa de Raphaël, et membre de Team Barth France*

Parce que j'ai trouvé une raison pour m'inscrire. Parce qu'il faudra bien trouver une raison ...pour le finir!

Tous les Ironmen/women ont eu un jour un moment d'excitation, celui de s'inscrire pour la première fois sur cette épreuve qui est réservée dans l'inconscient collectif à un groupe de dingues!

J'en a rêvé longtemps...j'ai toujours gardé l'image de mon prof' de tennis, Eric Plantin, qui s'était lancé il y a 25 ans dans le triathlon et

qui avait terminé 12ème à Hawaii. Je l'ai souvent regardé, souvent suivi et comme tous les enfants ...j'en avais rêvé! On ne rêve pas de triathlon comme on rêve des autres sports...on ne soulève pas des coupes devant des millions de spectateurs, on ne court pas devant un stade hurlant...on rêve simplement de passer une ligne d'arrivée (même en rampant dans la nuit!) et d'entendre crier "you are an Ironman!"

Mais on sait d'avance que le rêve se transformera aussi en cauchemar, le cauchemar du deuxième semi-marathon après plus de 200 kilomètres dans les jambes...et il faudra passer la ligne d'arrivée pour que le cauchemar soit oublié instantanément et redevienne rêve absolu!

Qu'est ce qui fera alors avancer le triathlète dans ces derniers kilomètres? La motivation!

Chacun trouve sa motivation où elle est...dans une image de vacances, dans les bras de son amoureuse ou de son amoureux, dans les encouragements de ses amis... ou dans les yeux d'un enfant. J'ai un petit garçon qui est atteint d'une maladie orpheline qui s'appelle le syndrome de Barth. Il ne courra jamais de Triathlon car son corps ne le supporterait pas...Il n'a que 2 ans et ne sait pas encore qu'il ne pourra malheureusement jamais imiter son Papa mais son Papa court pour deux car sa motivation se trouve dans ses yeux!

Le Triathlète est un sportif égoïste...il court avant tout pour lui, pour son dépassement...pour accomplir son rêve mais il a besoin d'aide dans les derniers kilomètres pour aller chercher cette ligne d'arrivée. Sur un Ironman, tout le monde souffre...du premier au dernier... personne ne se ballade...tout le monde recherche une motivation, une raison d'avancer.

Même si ma démarche est très anglosaxone (Les "charities" sont nombreux sur Marathon!) et qu'elle suscitera des réactions pas toujours très heureuses...je partage ma Motivation. Je ne partage pas mon petit garçon mais je partage volontiers sa maladie, la motivation qu'il me procure et le bonheur de voir son Papa et ses potes courir pour lui!

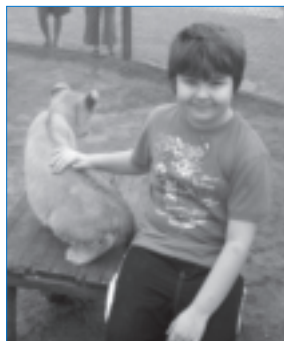
Le 26 juin prochain à l'occasion de l'Ironman de Nice, une équipe de sur-motivés courra aux couleurs d'un petit garçon dont le corps fait l'Ironman tous les jours.

Même si votre vie déborde de motivation, je vous en échange encore un peu...ça s'appelle les yeux d'un enfant qui vous remercie et qui espère que votre aide permettra à ses docteurs de trouver des remèdes pour que son corps fasse un peu moins l'Ironman!

\* Voir page 33 pour la traduction anglaise de cet article.

# Sibling Spotlight—Friends from Around the Globe

Below are the profiles of two of our fantastic Barth siblings — a very important part of our Barth community.



**Name:** Matthew, age 9

**Where are you from?**  
Romsey, UK

**What are your hobbies?** I sing in the Romsey Abbey Choir. I also do Judo. I like hanging out with my friends, playing Wii and DS.

**Affected sibling?** Nicholas, age 12

**What do you like doing with your brother?** He plays with me, doing lots of different things like playing on the Wii. We wrestle and have tickling fights. We go to the park together – I go on my bike and Nick goes on his quad bike. He's a great cook and I love eating all the things he makes!

**If you met someone who had just found out that their brother had Barth syndrome, what would you say to make them feel better?** I would explain that having Barth syndrome can make you tired and it's not the same kind of tiredness I have. But you can still do LOTS of things together and you can have lots of fights and lots of fun, just like with any other brother.

**What does the Barth Syndrome Trust/Barth Syndrome Foundation (BST/BSF) mean to you?** BST helps my brother and my friends who have Barth syndrome. I love going to the Bristol clinics because they're cool. We get to stay in a hotel, we play all day and we see all our friends.



**Name:** Ben, age 18

**Where are you from?**  
Virginia, USA

**What are your hobbies?** I adore surfing the magical waves of the ocean, experimenting with food, going to the movies to be enlightened by the latest film, mingling with people, and spending copious amounts of time relaxing at the beach.

**Affected sibling?** Andrew, age 22

**What do you like doing with your brother?** I love to spend the day cracking jokes, stepping outside to shoot some hoops, going to the beach to catch a tan, engaging in an intense game of football, and eating dinner all with my brothers.

**If you met someone who had just found out that their brother had BTHS, what would you say to make them feel better?** I would tell them they should feel a huge weight lifted off their family because they are now blessed with a diagnoses and are now part of a fantastic organization, a family, that has set out to help all the affected boys. I would also tell them that they are no longer alone and have plenty of wonderful people to converse with and question. I would tell them they can now relax a little bit because they finally have an answer to their mystery. And lastly that I'm here for them.

**What does the Barth Syndrome Foundation (BSF) mean to you?** BSF is not just an organization but a family and a loving one. It means the world to me to know there is a bunch of people in the world all looking out for one another and especially all the affected boys.

## Donations Made Easier

**Donate via Check:** Make check payable to **Barth Syndrome Foundation, P.O. Box #582, Gretna, Nebraska 68028**

**Donate On-Line:** You may donate to BSF or any of the international affiliates by going to our website, [www.barthsyndrome.org](http://www.barthsyndrome.org), and clicking on the 'Support BSF' link on our home page, or through Network for Good ([www.NetworkforGood.com](http://www.NetworkforGood.com)) where donors search for BSF by name.

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**Planned Giving:** One of the best ways to support our continued efforts is to remember BSF (or its affiliates) in your estate planning. Talk to your lawyer or estate planning professional about including BSF (or its affiliates) in your will.

BSF is an accredited member of BBB



[bbb.org/charity](http://bbb.org/charity)

# Power of Kindness



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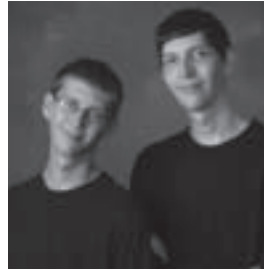
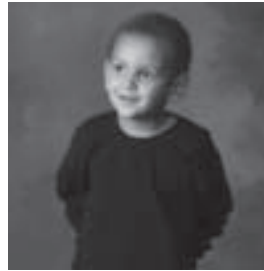


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 Abblas, Henk  
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 AME Association of Ontario  
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 Annis, John  
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 Assante Wealth Management  
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 Babcock, Mike  
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 Berezky, Andrea  
 Best, Cathy  
 Best, Rance  
 Bingham, Joan  
 Blacklaws, Matthew  
 Blake, Al  
 Blake, Joanne  
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 Bridger, Dianne  
 Bridger, Marj  
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 Browman, Stan  
 Brown, Danielle - Latitudes Plus Travel  
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 Landscapes Inc.  
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 Cattelan, Valerio  
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 Chalmers, Stephanie  
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 Chapman, Rick  
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 Chen, Chee  
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 Cherniak, Benjie  
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 Cooper, Jocelyn

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 Day, Margaret  
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 Duclos, Bev  
 Dvorkin, Gary, Peel Scrap Metal Recycling Ltd.  
 Ebata, Lyle  
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 Elwood, Rick  
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 Gilmour, Paul - Precision Aero  
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 Gordon, Travis  
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 Harris, Sandy  
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 Lindberg, Gunner  
 Lindsay, Sue  
 Lister, Verna  
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 Marcucci, Gabe  
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 Moe Limo  
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 Morris, Ian - Jones DesLaurier  
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 Murphy, Tony - Senior Extravaganza  
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 Nagel, Siegfried  
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 Noddle, Norm  
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 Olorenshaw, Neil  
 Olson, Sharon  
 O'Reilly, Patrick  
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 Paczkowski, Taisia  
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 Poitras, Sandi  
 Poole, Bob - Aerostructural Inc.  
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 Rantz, Rick  
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 Ross, Barbara  
 Roy, Larry  
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 Schuller, Dana  
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 Scott, Bob - Mx Aerospace Services Inc.  
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 Segal, Joseph  
 Segal, Mona  
 Selkirk, Kim

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 Smith, Christine - Tim Horton's Havelock ON  
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 Smith, Ted  
 Smolic, Alex  
 Smolic, Joe  
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 Sproat, John  
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 Staring, A.  
 Stevens, Mike  
 Stewart, Cal - Havelock Foodland  
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 Tocco, Carlyne - Great West Life  
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 Tomlinson, Danny  
 Tomlinson, Shannon  
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 Toth, Matt  
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 Trim, William  
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 Tsilikas, George - Kelsey's 7066  
 Turner, David & Cathy  
 Turner, Ron  
 Tweed, Scott - Medical Post  
 Tyers, Byron  
 Tyers, Robert  
 Vanderwater, Barbara  
 Vassallo, Jonas  
 Vella, Betty  
 Vincent, Suzanne  
 Warden, Stephen  
 Warren, Janet  
 Warren, Jerry  
 Weaver, Joan  
 Webb, Lindsay - Lindsay Webb Financial Inc.  
 Weeks, Jane  
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 Weller, Sharon  
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 Wild, John  
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 Wright, Jessica  
 Wuthrich, Grace  
 Ye, Jean  
 Yorston, Diane  
 Yorston, Robert  
 Young, Dorothy  
 Young, Lenore  
 Young, Ron  
 Zavitz, Peter



## Barth Syndrome Foundation

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# Do you know a boy with this genetic disorder?



Featured (L-R) are siblings  
John (age 10), Benjamin  
(age 15), and Daniel (age 5)

### Barth syndrome (BTSH; OMIM #302060)

A rare, serious, genetic disorder primarily affecting males. It is found across different ethnicities and 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 includes combinations and varying degrees of:

- **Cardiomyopathy** (*usually dilated with variable myocardial hypertrophy sometimes with left ventricular noncompaction and/or endocardial fibroelastosis*)
- **Neutropenia** (*chronic, cyclic, or intermittent*)
- **Underdeveloped skeletal musculature and muscle weakness**
- **Growth delay** (*growth pattern similar to but often more severe than constitutional growth delay*)
- **Exercise intolerance**
- **3-methylglutaconic aciduria** (*typically a 5- to 20-fold increase*)
- **Cardiolipin abnormalities**