

## All aboard: *On Track Toward a Cure*

BSF Fourth International Scientific, Medical and Family Conference  
July 21-26, 2008 - Clearwater, Florida

### Overview of Family Sessions

By Jan Kugelmann, Conference Coordinator

We would like for you to meet , Michael, age 4, one of the many 'faces' of Barth syndrome.



Photo by Amanda Clark

The BSF International Conference is a must-attend event. It will provide you with opportunities to learn from the experts about the ins and outs of this disorder and to meet other families from around the world. The location we have chosen for this conference offers a wonderful parallel to our own journey. Join us on July 21-26, 2008 at the Belleview Biltmore Resort in Clearwater, Florida and get on track toward a cure ... The journey is one you'll never forget.

#### Barth Clinics (July 22-23, 2008)

Once again BSF will be offering two days of clinics. Families will have the unique opportunity for private consultations with the experts to address specific personal concerns. No where else can you find such a concentration of doctors who specialize in the various aspects of Barth syndrome. At the same time, critical data will be collected to advance vital research on the disorder.

*(Cont'd on page 4)*

### Overview of Scientific and Medical Sessions

By Matthew J. Toth, PhD, BSF Science Director; BSF Affiliates' Science Advisor

Scientific and medical progress has been remarkable since the founding of the Barth Syndrome Foundation in late 2000 and the start of the International Barth Syndrome Conferences in 2002. However, there is still much more that needs to be learned about this underdiagnosed X-linked metabolic disorder with symptoms such as cardiomyopathy, neutropenia, growth delay and excessive fatigue.

On July 24-25, 2008, at our Fourth International Scientific, Medical and Family Barth Syndrome Conference, the world's leading researchers and clinicians will give presentations on many topics ranging from advances in understanding the underlying biochemistry, to the latest findings utilizing various model systems, to improving clinical aspects of this disorder.

*(Cont'd on page 5)*

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# President's Letter

By Valerie ("Shelley") Bowen, President, Barth Syndrome Foundation, Inc.

There is no greater motivation to achieve more, to be better or to do what is right than to help others. When we began this journey, we were a fledgling group with great aspirations, dreams and hopes for a better future for those who have Barth syndrome. Now we are a global community of families, friends, doctors and researchers bound together by commitment, compassion, concern and a track record of making noticeable progress in knowledge about Barth syndrome. Scientific advances are being made as a result of our efforts, and knowledge is being disseminated more widely through our programs. Today, there is no longer a single charity, but four organizations registered around the world with a shared mission. We have accomplished much, but there is still very much more to do.

Over the past months, a child within our group awaited a heart transplant. On Thanksgiving Day in the United States, he received this gift of life. We count our blessings! Just one decade ago, this would have been less likely since lack of knowledge about the disease often disqualified an individual with Barth syndrome from being a candidate for a heart transplant. Our efforts to educate the pediatric community about successful cardiac transplants in Barth syndrome patients have had an impact.

But the needs of those who have Barth syndrome are evolving and expanding. Two decades ago, this disorder was considered fatal in infancy. Now, through medical advances, however, boys who once had little hope of surviving beyond their infant years are becoming men. They are being called 'new survivors'.

The day after Thanksgiving, we learned that one of our 'new survivors' is also in need of a heart transplant. In this case, it would seem that our education of the adult medical community about successful transplants has not been as effective as with pediatric specialists, since this young man was denied a transplant because of his diagnosis of Barth syndrome. This situation is being resolved as I write, but the point is that young men with Barth syndrome face new challenges with their transition into the adult healthcare system that is completely unfamiliar with the disorder. This is one of the new areas where we need to direct some effort.

We are thankful for our achievements; they would not have been possible without your partnership in our mission. However, we will not rest on our laurels, knowing that we still have a long way to go. We invite you to stay with us and to continue to help us on our journey.

## **Late Breaking News: Social Security Holds First Disability Hearing on Compassionate Allowances**

Shelley Bowen testified on December 5, 2007 before an eminent panel in Washington, D.C. to advocate for those affected by Barth syndrome and millions of others affected by rare diseases in the United States. This testimony was part of the Compassionate Allowances Initiative which was unveiled on July 31, 2007 by Michael J. Astrue, Commissioner of the Social Security Administration. The experts presented testimony and shared their views about Social Security's efforts to identify and implement "compassionate allowances" for children and adults with rare diseases. (*Please go to [www.socialsecurity.gov/compassionateallowances](http://www.socialsecurity.gov/compassionateallowances) for testimony from many of the rare disease experts and a photo gallery of the hearing.*)

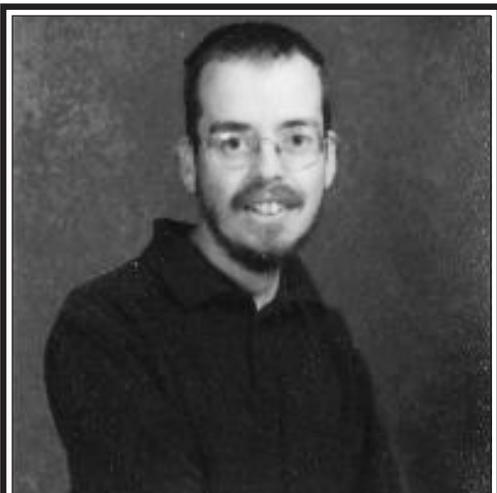
See page 24 for more news about our determination to advocate for rare diseases.



# Living with Barth syndrome

## The transition into adulthood

By Chris Hope, Co-Chair, BSF Family Services and Jason, Ontario, Canada (Age 29)



Jason works on staying active to help his endurance ...at times he has pushed himself in his desire to not let the syndrome control him ...he is determined not to let it stop him from doing what he wants to do with his life.

There are certain people who are outstanding. Twenty-nine year old Jason is one of them. He is a young man living a typical life, who just happens to have Barth syndrome. His story is similar to many others with the disorder. When he went into congestive heart failure at seven months of age he was simply diagnosed with cardiomyopathy and no other information was given. It would take a number of years until his parents learned of other children who had been found with this disorder, and that it had been given the name "Barth syndrome". Jason has been involved with the Barth Syndrome Foundation since its beginning, and has always demonstrated his incredible and independent spirit. He has managed to live quite 'normally' for most of his life, and is bent on it continuing that way.

Jason started public school at age five, and continued through to graduation using a few of the typical adjustments most students with Barth syndrome use — an extra set of books, leaving one class early so he could get to the next one in time, etc. Jason did quite well in school, especially with the more theoretical subjects such as psychology and sociology as opposed to the cut and dry subjects of math and science. He ended up repeating two grades due to illnesses, and graduated high school at age 20. When Jason was 17, he had a major set-back which involved a perforated small intestine, and he went into congestive heart failure. Once he started G-CSF his quality of life improved greatly. After graduating from high school, Jason went to Humber College part-time to train as a Developmental Services Worker, which allows him to be a special needs teacher assistant. He, therefore, knows how the school system works both from the perspective of a child with special needs and from the perspective of a professional working with special needs children.

Jason works in a public school assisting both the kindergarten and grade one teachers, as well as volunteering his time at church. He has never let Barth syndrome rule his life. He works at staying active to help his endurance, and at times he has pushed himself in his desire to not let the syndrome control him. He is determined not to let it stop him from doing what he wants to do in life.

Jason has always been open about his experiences of living with Barth syndrome, and passed on suggestions to parents of younger children with Barth, as well as encouragement to the older guys, especially letting them know: 'Yes, you can.' He attends events that BSF of Canada holds whenever he can, and has also helped man an awareness booth at a professional medical meeting in the spring of this year.

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# On Track Toward a Cure ~ Family Session Overview

(Cont'd from Cover)

## Family Sessions (July 24-26, 2008)

The family program will include presentations of the most up-to-date information on Barth syndrome. There will be sessions on research, cardiac and arrhythmia concerns, hematology and clinical manifestations of the syndrome and how to treat them. Additionally, occupational and physical therapy, nutrition and practical daily issues will be addressed. Families will have the opportunity to ask questions and participate in smaller break out sessions to discuss everything from birth to adolescence, college and growing up with Barth syndrome. Here you will gain a better understanding of living with the complex symptoms of Barth syndrome and learn coping mechanisms and strategies from those who know best – the families themselves. Newly diagnosed families attending this conference will find the tools needed to care for their sons. Relationships made will support and endure for life. Older families will build on their knowledge and experience and be prepared for the next stage in their sons' lives.

## New Programs

There will be new programs for the young attendees. Affected individuals and siblings will have their own programs, designed by some of the participants themselves. They will have ample time to rekindle and strengthen friendships and form new bonds.

## The Venue - On Track at the Belleview Biltmore

Henry Plant, the prominent railroad and hotel entrepreneur, became successful through the strength of his dreams. He dreamed of a better life - a life occasionally blessed with safeguards and comforts. Families living with Barth syndrome also dreamed of a better life - one with the safeguards that knowledgeable physicians could offer and the comforts of knowing other families with Barth syndrome.

Henry Plant developed a vast transportation empire and was instrumental in restoring economic health to the south, turning the State of Florida into a thriving place of business and tourism. The Barth Syndrome Foundation developed a community of families and professionals, thereby building bridges around the globe – Australia, Canada, Europe, South Africa, and the United States. Just as those railroad lines connected the south to the north, BSF connects its members to one another.

**“At BSF’s Conference...we discovered a group of people who share their time, money, support and complete dedication to give every boy with Barth syndrome a better life.**

**...We are dedicated to helping BSF in any way we can.” - Telles Family, Texas, USA**

**“Each conference has proven to be an incredible learning experience for the entire family. ... We always leave with important information and are once again touched by the special people affected by, researching and treating this condition.” - Lynn Elwood, Canada**

**“Going to the 2006 Conference brought it home to my family how dedicated everyone associated with BSF is to helping our boys.” - Tommy Anderson, UK**

Enamored with Florida's Gulf Coast, Henry Plant chose a secluded site on a bluff overlooking Clearwater Bay near the Gulf of Mexico. Here he built one of the South's grand dame resorts – *Hotel Belleview*. BSF has chosen its international conferences to build our future – experts share, researchers unveil, families learn, partnerships are born, progress is made – lives are saved. How appropriate that Henry Plant's hotel will be the venue of our 2008 conference.

The Belleview Biltmore is a rustic yet plush Victorian seaside resort. This unique venue will give the families an intimate setting. BSF will have exclusive use of the meeting space, and the hotel will be predominately occupied by our group. Tours of the hotel provide fascinating tales of Henry Plant's expeditions as well as hotel curiosities....secret tunnels and hidden passageways. Although the secluded site seems far from the hustle and bustle, it is close to many local attractions such as Busch Gardens, Adventure Island and the Florida Aquarium. An hour's drive east brings you to the heart of Central Florida – Orlando – where you can enjoy all the thrills of Walt Disney World, Sea World and Universal Studios. Please join us for a journey that you will never forget.

## Register Now!

For room reservations, please call the Belleview Biltmore (727-373-3000 or 1-800-237-8947) and reference “Barth syndrome” when making your reservation to guarantee the reduced rate. To reserve your room on-line, go to <http://www.belleviewbiltmore.com>. Under the reservations icon click on “Group Reservations”. Enter Attendee Code: BARTH.

In addition, make sure you also register for this meeting with the Barth Syndrome Foundation on-line at [www.barthsyndrome.org](http://www.barthsyndrome.org). For assistance or further information, please contact [conference2008@barthsyndrome.org](mailto:conference2008@barthsyndrome.org).

# Barth Syndrome: *On Track Toward a Cure*

## Overview of Scientific and Medical Sessions

(Cont'd from Cover)



BSF's Science Director had the privilege of visiting with {L} Dr. Iris Gonzalez (*retired*) and {R} Susan Kirwin, Assistant Director, Molecular Diagnostics Laboratory, A.I. duPont Hospital for Children in Wilmington, DE where ongoing Barth syndrome research is taking place.

The Scientific and Medical portion of this Conference will bring together basic scientists, clinical researchers, treating physicians and health professionals to focus on the syndrome through a series of carefully organized sessions. There are numerous issues in all of these areas that continue to perplex even the most seasoned investigators, so this will be a very stimulating meeting that looks toward the future. In addition to these formal presentations, there will be a Poster Session (for more detail see "Call for Abstracts" on pg. 7).

### MAJOR AGENDA TOPICS

#### Topic 1

*"What is the biochemical role of the tafazzin gene?"*

**Ronald J. A. Wanders, PhD — Chair**

Professor of Enzymology and Inherited Metabolic Diseases, University of Amsterdam, Amsterdam, The Netherlands; Scientific and Medical Advisory Board, Barth Syndrome Foundation, Inc.

*Professor Wanders heads the renowned Laboratory for Genetic Metabolic Diseases at the AMC in Amsterdam. Several scientists in this lab have conducted interesting projects concerning the underlying biochemical causes of Barth syndrome and have done other work that is relevant to a fuller understanding of this disorder.*

#### This session will focus on:

- Mitochondrial localization of tafazzin
- Mitochondrial protein import dysfunction
- Protein-protein interactions with tafazzin
- Cell culture modeling of tafazzin dysfunction
- Oxygen-consumption and ROS production in tafazzin-defective cell lines

#### Topic 2

*"What roles do cardiolipin and other lipids play in Barth syndrome?"*

**Grant M. Hatch, PhD — Chair**

Director of the Lipid Lipoprotein and Atherosclerosis Research Group, University of Manitoba; Professor, Department of Pharmacology and Therapeutics; Department of Biochemistry and Medical Genetics, University of Manitoba, Winnipeg, Canada; Scientific and Medical Advisory Board, Barth Syndrome Foundation, Inc.

*Dr. Hatch's research interests focus on metabolism and pharmacological modulation of phospholipids (including cardiolipin) in the mammalian heart and cells in culture. He has published numerous papers on these topics.*

#### This session will focus on:

- Biophysical role of cardiolipin
- Cardiolipin and apoptosis
- Mitochondrial structure in Barth syndrome cell lines
- Tafazzin and phospholipid remodeling
- Cholesterol metabolism in Barth syndrome cell lines

(Cont'd on page 6)



*Will (far right - age 21) and Jack (1st row, age 14) visit with Dr. Richard Kelley (L) and Dr. Michael Schlame (R) at Dr. Schlame's laboratory at the NYU School of Medicine.*

# Barth Syndrome: *On Track Toward a Cure*

## Overview of Scientific and Medical Sessions

(Cont'd from page 5)

### Topic 3

**“What are the phenotypic consequences of tafazzin dysfunction?”**

**Richard I. Kelley, MD, PhD — Chair**

Professor of Pediatrics, Johns Hopkins University School of Medicine; Director, Division of Metabolism, Kennedy Krieger Institute, Baltimore, MD; Staff Physician, The Kennedy Krieger Institute; Director, Intermediary Metabolism and Clinical Mass Spectrometry Laboratory; Chair, Barth Syndrome Foundation Scientific and Medical Advisory Board

*Dr. Kelley is board certified in Pediatrics and Medical Genetics and specializes in the diagnosis and treatment of inborn errors of metabolism. His research focuses on the determination of the biochemical basis of both known and novel genetic disorders and on the treatment of selected diseases, including Barth syndrome, Smith-Lemli-Opitz syndrome, and disorders of mitochondrial metabolism. Dr. Kelley also is a co-founder of, and consulting geneticist for, the Clinic for Special Children, a charitable medical facility for the diagnosis and treatment of genetic disorders among the Amish and Mennonite populations of Lancaster County, Pennsylvania.*

#### **This session will focus on:**

- Exon 5 mutations of the tafazzin gene
- Suppressor analysis of the tafazzin deletion strain of *Drosophila*
- Role of PG in cardiolipin metabolism
- SHHF rats and tafazzin upregulation
- CL bloodspot assay for Barth syndrome diagnosis
- Tafazzin mRNA dysfunctions and Barth syndrome
- Role of cardiolipin dysfunction in Barth syndrome

### Topic 4

**“How many Barth syndrome patients are there and what is being done for treatment?”**

**Barry J. Byrne, MD, PhD — Chair**

Cardiology Director, Department of Pediatrics, Shands Children's Hospital, University School of Medicine, Gainesville, FL; Professor & Associate Chair of Pediatrics, Molecular Genetics & Microbiology; Director, Powell Gene Therapy Center, University of Florida, Gainesville, FL; Scientific and Medical Advisory Board, Barth Syndrome Foundation, Inc.

*Dr. Byrne is a pediatric cardiologist in the Departments of Pediatrics and Molecular Genetics and Microbiology at the University of Florida, as well as the Director of the Powell Gene Therapy Center. His laboratory is engaged in a comprehensive research effort in molecular cardiology with emphasis on the diagnosis and treatment of heart failure in infants and children. The program is aimed at genetic therapy*

*for treatment of inherited and acquired cardiovascular disease. As a model system, they are focusing on a fatal form of heart failure due to glycogen storage disease. These programs are being supported by the American Heart Association, Muscular Dystrophy Association, and the National Institutes of Health (National Heart Lung and Blood Institute; National Institute of Diabetes and Digestive and Kidney Diseases; and National Center for Research Resources).*

#### **This session will focus on:**

- Screening of the pediatric DCM registry for tafazzin
- Fetal loss and Barth syndrome
- Screening for Barth syndrome
- Heart transplants in Barth syndrome patients
- Psychological aspects of Barth syndrome
- Longitudinal studies of Barth syndrome patients

#### **Clinic Sessions**

Before this formal meeting begins several days of “clinics” will be held. During these clinics, families will provide medical data and biological specimens to be included in the IRB-approved Barth Syndrome Medical Database and Biorepository used for research, thus playing a pivotal role in furthering what is known about Barth syndrome. In addition, some approved researchers who are doing work on Barth syndrome will be permitted to gather specific clinical data needed for their research. This is a wonderful opportunity to move the science of Barth syndrome forward, since BSF's Conference is the largest gathering of patients with Barth syndrome in the world.

The Clinic days also afford some professionals the chance to see many Barth patients in one venue, which is a rare and extremely helpful experience. Knowledge about various aspects of this complicated, multi-system disorder can be advanced and thoughts about improved treatment approaches can be formulated by examining multiple patients. We are all in this together, and we can and do learn a great deal from each other.

**Please register for this Conference (and have access to reduced hotel room rates) by visiting the Barth Syndrome Foundation website at [www.barthsyndrome.org](http://www.barthsyndrome.org).**



## Fourth International Scientific, Medical and Family Conference

### Barth Syndrome: *On Track Toward a Cure*

# Call for Abstracts

The Barth Syndrome Foundation 2008 Scientific and Medical Conference Organizing Committee (COC) invites the submission of abstracts for poster presentations related to the scientific and/or clinical aspects of Barth syndrome. **The deadline for abstract submission is April 15, 2008.** All submitted abstracts will be peer-reviewed by the COC. Once accepted, the submitting author will be expected to present his/her corresponding poster at a specific time during the Conference.

Details of the submission process are available at [www.barthsyndrome.org](http://www.barthsyndrome.org).

All Conference registrants are encouraged to submit abstract(s)/poster(s) of their work. Relevant posters presented within the last two years at other scientific/medical conferences may also be invited to be displayed by contacting the COC with the details.

Travel stipends (up to \$750) will be available based on need as well as quality of the poster. Completion of an additional form (available on our website at [www.barthsyndrome.org](http://www.barthsyndrome.org)) is required to apply for this funding, and we particularly encourage young investigators (including doctoral and post-doctoral attendees) to apply for this feature of the Conference.

## Understanding the role of tafazzin and cardiolipin

### What is their role in expanding Barth syndrome research?

By Matthew J. Toth, PhD, BSF Science Director; BSF Affiliates' Science Advisor

As you know, the identification of a defect in the gene called **tafazzin** was an important milestone in better understanding Barth syndrome and in focusing research to find a treatment for this unique condition. Many rare genetic or inherited diseases (and some very common diseases with a genetic component) do not have a gene that one can point to as the source of the problem—having the tafazzin gene identified for Barth syndrome is a great advantage. That does not mean, as many in the popular press insinuate, that when you find a “disease gene” the “cure” is just around the corner. I wish it were so, but I have never known it to be true. Treatments or “cures” for human disease are often the result of hard work and serendipity.

Genes are pieces of DNA, and DNA is the blueprint or the diagram for life. When the blueprints/diagram are altered, then the building that the blueprints describe is also altered. Similarly, when the tafazzin gene is altered, the body is altered. Any alteration of the tafazzin gene is manifested as an alteration in **cardiolipin** — an oily/fatty substance that makes up part of the cells of your body. Cardiolipin is only found in specific parts of the cell called the mitochondria. The mitochondria are contained within the cell and are involved in turning food into energy. If a defect in the tafazzin gene causes Barth syndrome, then one effect of this cause is a change in cardiolipin. The defective tafazzin gene also causes other effects, but for now the one effect we have the most knowledge about is cardiolipin.

So how is cardiolipin involved with the symptoms that the Barth patients have to endure like cardiomyopathy, excessive fatigue, growth delay, neutropenia, *et cetera*? The short answer is we do not know — that is why we are doing research. We know that cardiolipin is found in mitochondria, and mitochondria are needed to turn food into energy, so perhaps when cardiolipin is altered the body's ability to turn food into energy is also altered — makes sense! However, we need to test this hypothesis rigorously using the scientific method. We also need to be aware of how we may be able to fix the problem of cardiolipin dysfunction. The research being done today is measuring how cardiolipin and cellular energy are related, why neutrophils are lacking, what the mechanisms that cause Barth syndrome cardiomyopathy are, whether a mammal can get Barth syndrome, etc. The answers to these questions will allow the scientist-physician to better understand and to better treat patients with Barth syndrome. With hard work and a little luck we may be able to find a specific treatment that can reduce or eliminate many of the symptoms the Barth syndrome patients have to endure.



# Physician awareness in 2007

By Stephen Kugelmann, VP, Awareness, Barth Syndrome Foundation, Inc.



Kate McCurdy and Dr. Matt Toth represent BSF at the Child Neurology Society Annual Meeting.

Our attendance at the American College of Medical Genetics Conference last spring was most rewarding. We were approached by a physician who had recently diagnosed a patient in Taiwan. The physician was very excited to talk with us and has since put us in contact with the affected individual's family. Immediately following this conference we attended the Society of Inborn Errors and Metabolic Diseases Meeting. Exhibiting at this narrowly focused area of science provided an opportunity for further exposure of Barth syndrome to specialists in metabolic disorders.

The Child Neurology Society held their annual meeting this past October. As a repeat exhibitor, we have managed to establish a very good relationship with those who have attended over the years. The attendees now make it a point to visit our exhibit to seek up-to-date information. This is a significant change from years past when we would consistently get asked the question, "What is Barth syndrome?"

In November, our attendance at the American Heart Association's Scientific Sessions provided us with another opportunity to network. At this meeting, Carolyn Spencer, MD, Assistant Professor Pediatrics, Department of Cardiology, Children's Hospital, Boston, MA, presented a poster summarizing a portion of her research funded by BSF. We ended our year of physician awareness at the American Society of Hematology Annual Meeting on December 8th – 10th, where Andrew Aprikyan, PhD, Research Assistant Professor, University of Washington, School of Medicine/Hematology, presented a poster focusing on neutropenia and its relationship to Barth syndrome. Awareness has also been raised at medical conferences by our funded researchers during presentations, directing the audience to our exhibit booth for further information.

Physician Awareness planning for 2008 has begun and we look forward to another spectacular year. The international exposure that we gain by attending professional conferences also feeds our other programs. Science and Medicine benefits with potential new grant recipients. Family services benefits through direct contact with the diagnosing or treating physicians. Any and all awareness efforts will continue to support our mission.

Please refer to pages 14-15 (UK/Europe), 18-20 (Canada), 20 (S. Africa) and 25-27 (regional outreach) for more detail about our regional awareness efforts.

## Revised Healthcare Professional Brochure

By Kate McCurdy, Board Member, Barth Syndrome Foundation, Inc.

Inserted in this Newsletter 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.

Personally, I am expecting to distribute this new brochure to each of my son's doctors and also to keep several in the folder I have prepared to take with us if we need to visit an Emergency Room. The brochure will also be distributed by BSF at professional conferences where we have a booth. If anyone — family, physician, scientist or donor — would like some additional hard copies, please contact Lynda Sedefian at [lsedefian@barthsyndrome.org](mailto:lsedefian@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.

(Note: The Canadian and UK/European version of this revised brochure will be distributed in the near future.)

# Barth Syndrome Foundation Family Services

## Supporting families around the world

By Chris Hope and Shelia Mann, Co-Chairs, Family Services, Barth Syndrome Foundation, Inc.

As we come to the end of another year, it is time to reflect on what has been accomplished, and all that we still need to do. This year we have spoken with families from all walks of life, in many different countries around the world. We have been contacted by several families in South America, and with the help of Iris Gonzalez, PhD, Molecular Diagnostics Laboratory (retired), A. I. DuPont Hospital for Children, we have been able to help these families in their quest for a diagnosis for their children.



Rosemary, Shelia and Kate enjoyed an afternoon of 'catching up' while at the Dunn's home - a closure to BSF's Northeast Family Gathering .

### Physician Database

Another initiative that Family Services is working on is adding all of the doctors who are treating a Barth patient into the database. The Foundation has been creating treatment guidelines which, once approved, will be distributed to all physicians within our database. If you would like to provide your son's physician(s) contact information, please send it to Chris Hope or Shelia Mann ([chope@barthsyndrome.org](mailto:chope@barthsyndrome.org); [smann@barthsyndrome.org](mailto:smann@barthsyndrome.org)).

### Resource Binders

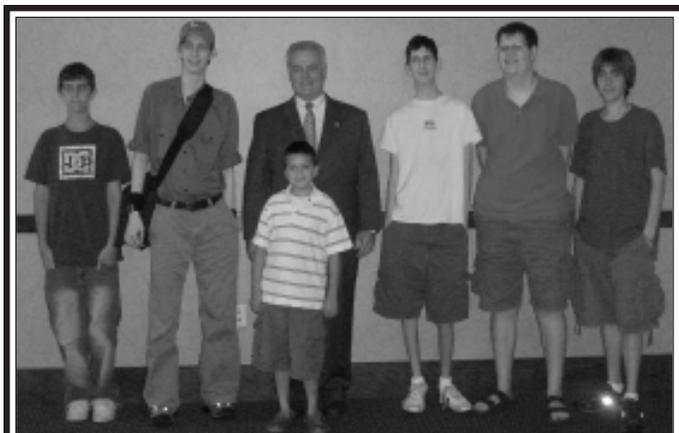
As we continue to help families looking for a diagnosis, our focus is directed on those who have been identified. For the last several years, the Family Services Team has been preparing a series of fact sheets on many of the components of Barth syndrome. We are very happy to say that we are now in the final stages, and families will be receiving a resource binder before the end of this year.

We now have families who have been with us from several months to seven years. This, in itself, caused a dilemma when trying to create the material for this binder — if we made it too simple, it would be of no use to experienced families — if we made it too in-depth, we would not be helping our newer families. We hope that we have reached a balance which will be beneficial to all, and look forward to getting feedback from you.

This year has been a trying time for some of our families, and we extend our sincere thoughts and hopes for recovery to them. We celebrate when we hear that someone is doing well, and we wait with baited breath when the news comes that one of our boys is in need of surgery or other medical attention. The great news for this year is that not one of our boys or young men with Barth syndrome has passed away this year.

Our numbers are growing, and we now have people in our database ranging from 7 months of age to 42 years! There are 17 young men in our group who are 20 years or older. Certainly something to think about when just a few short years ago we were told the disorder was fatal.

Globally there are 111 living affected individuals in our database. With all affiliates, we support families in Austria, Australia, Belgium, Canada, the Czech Republic, Denmark, France, Germany, Israel, Italy, Kuwait, Portugal, South Africa, Taiwan, The Netherlands, United Kingdom, and USA. We look forward to continuing to support families, and hope to see many of you in person at the 2008 Conference.



(L-R) Derek (14), Will (21), Jack (14), Kevin (18), John (25) and Michael (21) gather with Mayor Harrington while attending BSF's Northeast Outreach in Brockton, MA.

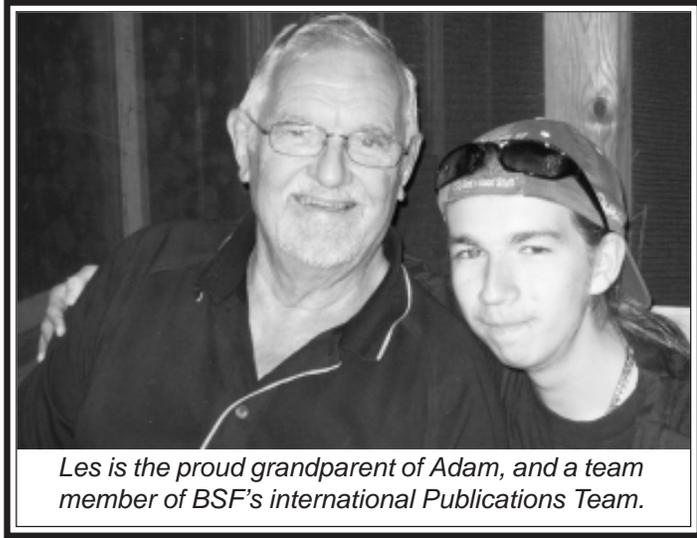


(L-R) Chris, Jan, Kate, Dick, Terry, Anna and Laurie enjoy a Sunday afternoon at the Dunn's home at the end of BSF's Northeast Outreach weekend.

# A heartfelt 'Thank You' to our volunteers

## Volunteering has its own rewards!

By Les Morris, BSF Publications Team Member, Canada



Les is the proud grandparent of Adam, and a team member of BSF's international Publications Team.

As a principal of several inner city schools in the city of Toronto, I was continuously impressed with my parent volunteers who did everything for my students. They supervised lunch rooms, flooded outdoor ice rinks, ran fun fairs and helped the teachers in the classrooms.

Their examples alone put the spirit of volunteering in me but becoming a volunteer for the Barth organization was easy for me because I am the proud grandfather of a Barth boy, Adam.

There is, however, more to the story. It began some 48 years ago with the birth of my first son. From the beginning he was not well and spent most of his early days in Toronto Sick Children's Hospital. The daily visits were difficult but one day the good news came that he was well enough to come home. He was home for a short time but didn't make it. He was two years old.

I was later blessed with a healthy daughter and son, and in time my daughter had our first grandchild, a boy. He is a very special Barth boy who will be eighteen this December. Now that I am more involved and know so much more about the Barth community, I have an even better sense of what the parents, the boys, young men and their siblings are going through. As a result, I am now not only volunteering on behalf of my extended family, but I also have the great satisfaction of being a member of a fantastic team of people here in Canada and around the world who are working toward a cure for Barth syndrome.

## Publications Committee - Volunteers collaborating across the world

By Nigel Moore, BSF Publications Team Member, England

Never volunteer! Popular advice which is wrong. Working as volunteers on the Publications Committee along with Les Morris and Lorna Moore under our Chair, Lynda Sedefian, is inspiring, stimulating and deeply satisfying.

The Publications Committee serves all other programmes, Science and Medicine, Awareness and Family Services, as well as the Fundraising Committee. We capture and disseminate the results of the labours, the aims and dreams of all at the Barth Syndrome Foundation and affiliates through written publications and the website. It is interesting work, crossing international boundaries, bringing together families and professionals, volunteers and donors. We are helped by a number of translators and occasional volunteers in the endless task of making our information available to all.

We edit and proofread articles with help and advice from our scientific and medical professionals and the Board. We try to be sensitive to the needs of the intended readers, the purpose of the publication or article and the style and tone of the original copy. If the article does not inform, inspire, persuade, amuse or interest as the author intended, then we have failed.

Lorna and I have been involved in some of the diverse publications produced by the Barth Syndrome Foundation and the Barth Syndrome Trust (UK and Europe). We have worked with Jo van Loo in Holland on documents for Europe and we are directed by Michaela Damin in the production of UK-specific material.

Lorna was invited to join this committee because her skills would help make the Publications Team so much stronger, but it is impossible to list all the skills and knowledge we have acquired through our volunteering, whether by formal training or 'on the job'. Words such as 'haematology', 'neutropaenia' and 'hypoglycaemia' (yes, all with an a!) are now part of our everyday vocabulary.

When Anglicising BSF publications, we often joke that we are 'divided by a common language', but we know that more importantly, we are united by a common cause.

### Volunteers welcome!

Would you like to join the Publications Team or help occasionally? Do you have any experience, talent or skills to offer? Or perhaps you have no particular experience but are interested in our work. Please contact us for an informal chat with no commitment at: [bsfpublications@barthsyndrome.org](mailto:bsfpublications@barthsyndrome.org).



# Valuable, valiant, vehement and venturesome The Canadian volunteers!

Our Canadian volunteer program is a mere eight months old and already has had mammoth results. We started a journey with this enthusiastic group by having a gathering at one volunteer's house and explaining our "wish list" of places where their help would be beneficial. Eight months later we gathered again at another volunteer's house and were able to show them how they had factored greatly into each of our core programs.



Their actions and efforts were instrumental in:

- making or soliciting prizes for our golf tournament
- helping to organize and run the golf tournament
- arranging for free printing of letterhead, receipts and publications
- helping to co-ordinate the poinsettia sale
- finding us corporations/banks to write to for corporate donations
- running independent fundraising and awareness events
- helping us to be stronger and more vital

Our volunteers have given us the benefit of their experience, their many talents, their wonderful ideas and their endless enthusiasm. We are thrilled to be working along side such a caring and devoted group of people! Thank you!! We look forward to 2008 and future shared initiatives.

Those Canadian volunteers who were able to join us on November 3 were Marj Bridger, Wayne Bridger, Bill Clelland, Audrey Hintze, Les Morris, Maureen Pitkethly and the BSF of Canada Executive. Other volunteers, Bob and Susan McJannett and friends, are making plans now for a Silent Auction Evening for BSF of Canada at the Speed-O-Rama Car Show this coming February in Toronto.

We thank Michaela Damin for her guidance and mentorship as we started this journey in the early part of 2007. Shelley Bowen is also to be thanked for continually encouraging us to add family members, friends and others to our volunteer base.

We would like to remind everyone of the fact that - **Volunteers Live Longer!** If you haven't tried volunteering with us yet... please feel free to contact your nearest Barth syndrome affiliate!



## The sweet taste of success

*By Stephen McCurdy, Chief Financial Officer, Barth Syndrome Foundation, Inc.*

If you had never tried chocolate before... if you had never seen or heard of it... would you try it without any urging from your friends who had? Brown, gooey or hard, in its purest form, it can be quite bitter. It doesn't sound very inviting or appetizing by itself does it? But mix it with a little sugar, maybe some milk, it can become one of life's great rewards and can enrich and improve so many things!

Well, fundraising is a little like chocolate. It can be tough to get people to try it. Raw, without any other ingredients, it can seem too bitter. But when linked to a powerful cause like Barth syndrome, when inspired by the stories of the boys and young men who remain cheerful, optimistic and wise despite their chronic illness, and when creatively mixed with challenging or enjoyable events, fundraising can actually taste quite sweet! So, fundraising as the "chocolate" of BSF? Ask the people whose stories follow and you may change your mind. It's not as much of a stretch as you may think! Try it... you'll like it! *(Cont'd on page 12)*



*Photo taken in 2005*

Ashley is loving his first taste of chocolate. I believe he is thinking ...  
"Try it...you'll like it!"

# The sweet taste of success

(Cont'd from page 11)



## John and Liz Higgins — Bowling for Barth

John and Liz Higgins and their entire family have been a part of BSF since before it was formed. With their son Jack and Liz's parents they attended the first informal gathering of Barth families in Baltimore and have been actively involved ever since. In October, the Higgins family held their Fourth Annual Bowling for Barth fundraiser. For the Higginses, bowling is a great way to gather their friends together for some fun, a little competition and to raise some money for BSF. And John never looked better in his bowling shirt! Their friends are already looking forward to next year's Bowlathon!

## Ed Pace — Friend of Scott Oldewage and BSF

Ed Pace, owner of Lake City International Trucks has been a long time supporter of BSF because of Scott Oldewage, a Barth dad and one of LCI's employees. Watching Scott deal with his son's illness, Mr. Pace had come to understand and appreciate the challenges of raising a child with Barth syndrome and being a dedicated employee at the same time. He instituted a very generous payroll deduction system where anyone who wanted to contribute a little bit to BSF each payroll period would have their contributions matched by LCI, and many of Scott's colleagues signed up. But Ed Pace went further, pledging to contribute \$500 to BSF each month that LCI turned a profit. He hasn't missed a month yet. Company golf tournaments and year end Holiday parties have become additional vehicles for having fun and doing a lot of good at LCI... and BSF benefits.

## Jan and Steve Kugelmann — Annual Golf Tournament

For the fourth time in as many years, Jan and Steve Kugelmann have hosted their Barth Syndrome Chopper Dropper and Golf Tournament in Merritt Island, Florida. Only 144 golfers can participate, and the spots go fast. Jan raises additional money by having local businesses sponsor each hole. There are longest-drive and closest-to-the-pin contests and a much-anticipated party afterwards where awards provide the opportunity for good natured kidding. But the highlight of the event has become the moment when the local police helicopter drops a bucket of numbered golf balls onto a green to see which one ends up in or closest to the hole. Each golf ball was "sold" for a \$50 donation, with the winner taking home half of the total raised and BSF retaining the rest. This year the winner was Judith Fuller who won almost \$3,500 – a very nice return on her "investment"!



## Laurie and Tom Monahan and Anna and Mark Dunn — The Boston Connection

If you were in the Boston suburbs of Brocton or Franklin, MA this summer, it would have been hard to miss BSF. At the Northeast Outreach event the Mayor of Brocton proclaimed it 'Barth Syndrome Awareness Weekend.' The Dunsns hosted a feast and concert in their back yard, and the numerous fundraising efforts of both families increased awareness and the ability to fund our rapidly growing research program, among others. Awareness and fundraising go hand in hand. Both of them help save lives and no one knows this better than these two families who were both among the first group that gathered in Baltimore in 2000.



(Cont'd on page 13)

## Randy Buddemeyer and C.B. Richard Ellis — Golf Tournament



The company Randy works for is a global leader in commercial real estate services. Giving back to the local and national communities in which they operate is a core value at C. B. Richard Ellis and their many suppliers and partners. 2007 was the second year that Randy organized the C. B. Richard Ellis Golf Tournament in Tampa, Florida to benefit the Barth Syndrome Foundation, more than doubling the donations he raised the year before. 144 golfers had a great time on a beautiful course, learned about Barth syndrome and helped make a major difference in the lives of boys and young men around the world... all because they know about Randy and Leslie and their son Andrew. Sometimes all you have to do is ask.

## Coach Gary and “Team Will” — Triathlon

Gary Rodbell is BSF’s Ironman. He has raced in three Ironman events and helped to raise over \$500,000 for BSF most recently in the 2006 Panama City Florida Ironman. Although still racing, Gary has now become “Coach Gary” to 14 budding triathletes collectively known as “Team Will”, after Will McCurdy from whom they all take inspiration. The team consists of Gary Rodbell, Paul Epstein, Matt Karp, Angelo Mancino, Heather Segal, Stephen Tunguz, Alan and Amy Rosen, Jack Steinberg, Reshmi Odouard, Jeff Knopping, Joanne Jensen, Kayleigh Monetti, Jaime Jofre and Laura Azar. This summer, they



participated on behalf of the Barth Syndrome Foundation in the Westchester Triathlon, an Olympic distance event held in Rye, New York, and they raised over \$30,000 in a few weeks almost entirely via on-line solicitations to their friends and e-mail lists. Coach Gary has already attracted a larger team for next year and they have begun training, which of course, requires periodic parties to keep everyone’s spirits up! Gary has modeled his team after “Team in Training”, a similar but much larger program that raises millions for Lymphoma and Leukemia each year. New triathletes and new chapters are all welcome!

## Randell Boys — Birthday Bash for Barth

Jay and Amer Randell, who have two boys with Barth syndrome, decided to turn their triplet’s birthday party into a fund raiser for BSF. They received donations from more than 75 friends who knew them and their boys and were happy to celebrate the boys’ continued health with a donation to the group that is single-mindedly devoted to making their future as healthy as possible!

## Memorials

With sadness and with thanks, we also acknowledge the contributions made to BSF in memory of friends that we lost in 2007. The families of Paula Varner, Rob Lochner and Tony Satula all felt strongly that the best recognition that anyone could make of the passing of their loved ones was a donation to BSF.

Paula Varner was Sue Wilkins’ mom and John Wilkins’ grandmother, and BSF’s first and very steadfast supporter. She quietly funded the first informal gathering of Barth families in Baltimore in 2000, from which BSF was born, and continued to provide her wisdom and support to Sue and BSF throughout her life. Although University of Nebraska blood ran through Paula’s veins, her family felt that donations to BSF would be the most appropriate tribute to Paula, and the University of Nebraska itself joined in.

Rob Lochner was Lynda Sedefian’s brother. He too, wanted to help Lynda and BSF before BSF was even officially formed and sponsored our first fund raiser in New York in 2000. Rob’s Mom, Joyce Lochner, and Lynda asked that donations be made to BSF in Rob’s name after his untimely death.

Tony Satula was a successful attorney with a major firm in New York and a friend of the McCurdy family in Larchmont, New York. Having been BSF contributors for many years, Tony’s wife, Debbie decided that contributions to BSF would be the thing that Tony would want most.

Each of these families had a strong connection to BSF, and in their sadness and grief, they thought of people they could help. We send them each our thoughts, prayers and sorrow for their loss and our heartfelt thanks for their thoughtfulness. We should all have such friends as these.



# The Barth Syndrome Trust

## 2007 ... What a wonderful year

*By Michaela Damin, Chairperson, Barth Syndrome Trust*

This year, more of our families, volunteers, doctors and donors have rolled up their sleeves and offered to help. We have become a very close group, all working well together to achieve our common goals. I wish to thank you for your dedication, generosity, enthusiasm and hard work.

### HIGHLIGHTS OF 2007

#### **Bristol Clinic - A centre of expertise for parents**

*By Ralph Easterbrook*



It is a great comfort for the families of children with Barth syndrome to meet and talk to other families in similar circumstances. The condition is so rare, that the feeling of being alone and abandoned upon being informed that your child suffers from Barth syndrome is quite overwhelming. The fact that there are other families who have experienced the same emotions and problems - and from personal experience can provide valuable practical as well as medical information - helps to reconnect one to the real world.

Further, it has proved a great blessing to my young children to meet others with Barth syndrome. They too feel comforted to know that they are not the only children affected. Through play and talk with the other boys, they have gained some insights into the condition without being frightened or apprehensive about the future, which would probably not be the case if they were given the same information by an adult.

The clinic provides a good informal way of discussing practical problems that have arisen and may arise in future. We can learn details of early symptoms of minor or major problems. It is also an excellent way to learn of the latest research and developments into the nature, cause and long-term medical thinking surrounding the syndrome.

It has fostered close bonds not only between the families involved, but also between the families and the medical staff. Indeed, the staff are regarded as being as much a part of the 'Barth syndrome family' as any of the families who attend the clinic. This leads to other benefits. As the medical staff seem approachable, information is imparted which may not be offered to other medical staff. What may seem trivial, embarrassing or plain silly may in fact turn out to be part of a larger overall pattern with unforeseen consequences.

The clinic also provides an in-depth medical analysis of each child, which looks at his health and well being as a whole. Unfortunately, but quite understandably, the local medical centres tend to treat each separate symptom as it arises, with little understanding of the underlying cause.

This syndrome can give rise to some quite startling differences in the severity of the medical problems, as I can personally testify to, being the father of two boys with Barth syndrome. These examinations also provide data for further study and comparisons. This, together with further research and increased funding, will lead to increased understanding of Barth syndrome, early diagnosis and the ultimate target - a cure.

Last, but not least, do not underestimate the 'feel-good' factor of this forum - it is nice to keep in touch by email, telephone etc., but it is as nothing when compared to meeting your friends face-to-face.

#### **Family and Volunteer Gathering – Saturday 7th July**

*By Michaela Damin*

After a whirlwind clinic day, it was wonderful to meet and talk, eat and relax together at Avon Valley Country Park for a barbecue and social day. Parents compared notes and asked all those questions they forgot to ask on the previous day at the clinic, volunteers met the people they help and children forgot all about Barth syndrome and went out to play together.



## OTHER NEWS

- We are continuing to work on a national and European level with various partners to raise awareness of Barth syndrome.
- We provide doctors with the information they need in order to diagnose and treat boys with Barth syndrome.
- Our Family Route Map (a document which signposts sources of information and services) is due for completion in December 2007 and will be offered to other rare disorder groups to use as a template for creating their own route maps.
- We had two successful volunteer workshops to coordinate our efforts.
- We have contributed \$35,000 towards approved research projects by scientists from Amsterdam, with further funds available for research in the UK and Europe.
- We have enrolled the UK patients into the Barth Syndrome International Medical Database and Biobank.

## FUNDRAISING NEWS

### 2006 Corporate Challenge - Coldstream Hills Winery, Australia

By Pam Holmes

I chose the Barth Syndrome Trust as “my” charity for our 2006 Corporate Challenge. The first challenge for us was to walk at least 6km a day. We, as a team, walked 12,873,289 steps – a total of 8,239km in a five month period. We all felt much better and fitter for it at the end.

The second challenge was to get sponsorship and donations for our hard work. Through a Matched Giving grant from my employers, the Fosters Group, the sum of \$1,372 that we raised as a team, was doubled to \$2,744.

As a personal contribution, I started a small catering business, called ‘Nicky’s Kitchen’, after my great nephew who has Barth syndrome – Nicholas Damin. I catered for Indian Dinner Parties and Cocktail Parties and raised \$990 for BST. I also ran a separate raffle of Yarra Valley products and raised a further \$303. A total of \$3,047 (£1,437) has been sent to the Barth Syndrome Trust. I will now begin raising more money and more awareness for BST in Australia.

### Fundraising in Belgium – Dinner for 250!

The Bruge family in Belgium celebrate their son’s birthday every year with a special fundraising event. This year, for his third birthday, they had a couscous dinner for 250 people and made 2,670 euros. Thank you to the family and their generous guests.

### Fundraising in Scotland

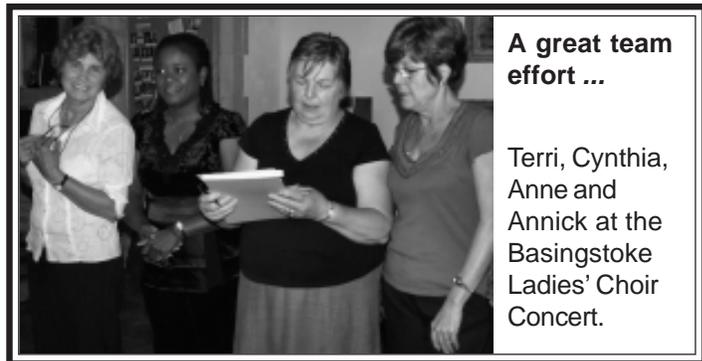
Tommy, Eleanor, and friends ran the Glasgow half - marathon again, with sponsorship of £908. Thank you to the GlaxoSmithKline Employees Charities Association for another donation of £200. *Tommy and his sister-in-law, Eleanor each have a son with Barth syndrome.*

## Fundraising in Bristol

For the last couple of years I have run the Bristol half-marathon, but it is hard to train for and even harder to run. It was difficult going back to the same people asking for sponsorship for something I had done before. I decided to ask local shops and pubs to hold a collecting tin for BST. I was a little nervous at first but I couldn’t believe it when 80% of those businesses I approached kindly agreed to take a tin.

I have had 20 tins in my area for about eight months and they have collected over £1,200. The best part is, I haven’t had to ask anyone for money, as people give their unwanted small change - *Dave has two sons with Barth syndrome.*

## Fundraising - In and Around Basingstoke



**A great team effort ...**

Terri, Cynthia, Anne and Annick at the Basingstoke Ladies’ Choir Concert.

Terri Allison, our fundraising coordinator, and the Basingstoke area fundraisers Anne Ward, Cynthia Condliffe, Heather and Richard Oram had another busy year.

We started with another of our popular quizzes in Overton run by Richard and Heather Oram. A donation of £200 from the Methodist community increased the total raised to £796.

Terri organised several fundraisers which brought in a total of more than £1,300 for the Trust: a tournament at the Oakley Tennis Club, a collection in Basingstoke, a Race Night and the raffle of a Christmas hamper.

Our most successful event this year was a concert generously performed for us by the award winning Basingstoke Ladies’ Choir. A raffle brought the takings from a most enjoyable evening to £1,334. Thanks to Anne Ward and her helpers - a great team effort.

We are grateful to all those who have supported BST so generously. Apart from raising funds, these events have the added benefit of informing the public about Barth syndrome. We would also like to thank the fundraising team and their helpers for their tireless work.

## IN CONCLUSION

Much great work has been done this year. Much still remains to be done. 2008 promises to be a busy and rewarding year for us all. Best wishes for a healthy and happy New Year.



# Awareness of Barth syndrome is growing exponentially

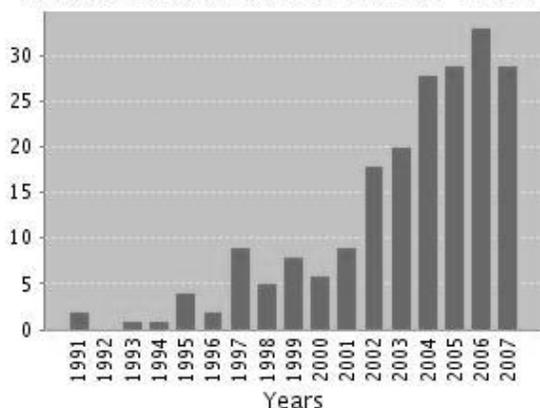
There has been a statistically significant increase in Barth syndrome related peer-reviewed journal articles published recently, which is due in part to BSF's successful research grant program. To date, there have been 19 journal articles published as a direct result of BSF funding.

Listed below are the latest articles added to BSF's library since April 2007:

- 1) Kulik W, van Lenthe H, Stet FS, Houtkooper RH, Kemp H, Stone JE, Steward CG, Wanders RJ, Vaz FM. **Bloodspot Assay Using HPLC Tandem Mass Spectrometry for Detection of Barth Syndrome.** Clin Chem. 2007 Dec 10; [Epub ahead of print].
- 2) Mancuso DJ, Sims HF, Han X, Jenkins CM, Guan SP, Yang K, Moon SH, Pietka T, Abumrad NA, Schlesinger PH, Gross RW. **Genetic Ablation of Calcium-independent Phospholipase A2{gamma} Leads to Alterations in Mitochondrial Lipid Metabolism and Function Resulting in a Deficient Mitochondrial Bioenergetic Phenotype.** J Biol Chem. 2007 Nov 30;282(48):34611-22. Epub 2007 Oct 8.
- 3) Philipp U, Broschk C, Vollmar A, Distl O. **Evaluation of tafazzin as candidate for dilated cardiomyopathy in irish wolfhounds.** J Hered. 2007;98(5):506-9. Epub 2007 Jul 9.
- 4) Yen TY, Hwu WL, Chien YH, Wu MH, Lin MT, Tsao LY, Hsieh WS, Lee NC. **Acute metabolic decompensation and sudden death in Barth syndrome: report of a family and a literature review.** Eur J Pediatr. 2007 Sep 11; [Epub ahead of print].
- 5) Hullin-Matsuda F, Kawasaki K, Delton-Vandenbroucke I, Xu Y, Nishijima M, Lagarde M, Schlame M, Kobayashi T. **De novo biosynthesis of the late endosome lipid, bis(monoacylglycero)phosphate.** J Lipid Res. 2007 Sep;48(9):1997-2008. Epub 2007 Jun 8.
- 6) Moric-Janiszewska E, Markiewicz-Łoskot G. **Genetic Heterogeneity of Left-ventricular Noncompaction Cardiomyopathy.** Clin Cardiol. 2007 Aug 29; [Epub ahead of print].
- 7) Postle AD, Wilton DC, Hunt AN, Attard GS. **Probing phospholipid dynamics by electrospray ionisation mass spectrometry.** Prog Lipid Res. 2007 May-Jul;46(3-4):200-24. Epub 2007 Apr 24.
- 8) Han X, Yang J, Yang K, Zhao Z, Abendschein DR, Gross RW. **Alterations in myocardial cardiolipin content and composition occur at the very earliest stages of diabetes: a shotgun lipidomics study.** Biochemistry. 2007 May 29;46(21):6417-28. Epub 2007 May 8.
- 9) Markiewicz-Loskot G, Moric-Janiszewska E, Loskot M, Szydłowski L, Weglarz L, Hollek A. **The letter of Finsterer and Stollberger was shown to the authors who replied.** Europace. 2007 Apr;9(4):256-7. Epub 2007 Mar 8.

## The scientific/medical community is paying more attention to Barth syndrome!

### Published Items in Each Year



The graph to the left displays the number of peer-reviewed articles mentioning "Barth syndrome" as keywords in a search using the ISI Web on Knowledge database.

It is clear that the awareness of Barth syndrome is growing at a rapid clip.

\*Feel free to visit [www.barthsyndrome.org](http://www.barthsyndrome.org), where we maintain an up-to-date, vast library of information as it relates to Barth syndrome and the various components of this multi-system disorder.

# NIH research initiatives seeking applications

In addition to vast investigator-initiated research that is supported by the National Institutes of Health (NIH) in the US, research in some specific areas is solicited by various NIH institutes from time to time. Applications for these are usually accepted three times a year.

The following ongoing NIH initiatives are particularly relevant to Barth syndrome. Please refer to the NIH website at <http://grants.nih.gov/grants/guide/index.html> for more details about these and other funding opportunities.

## Animal Models of NIDDK Relevant Disease (R01) PA-07-012

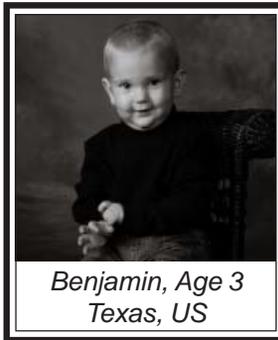
**Purpose:** To provide support for the development and validation of new animal models of NIDDK-relevant diseases (including diabetes, endocrinology, and metabolic diseases; digestive diseases and nutrition; and kidney, urologic, and hematologic diseases) where animal models are either inadequate or lacking. New and/or improved animal models should be designed to facilitate preclinical testing of diagnostic, preventive or therapeutic interventions.

## Development of Animal Models and Related Biological Materials for Research (R21 for pilot/exploratory projects) PA-07-336

**Purpose:** To develop, characterize or improve animal models for human disease that are of research interest to two or more categorical NIH Institutes/Centers.

## Structural Biology of Membrane Proteins (R01) PA-07-253

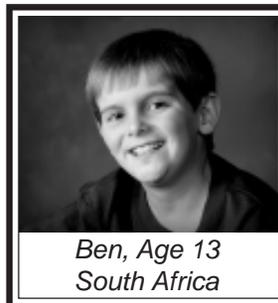
**Purpose:** To develop research and methods to enhance the rate of membrane protein structure determination and to determine specific membrane protein structures. Innovative methods for expression, oligomerization, solubilization, stabilization, purification, characterization, crystallization, isotopic labeling, and structure determination of unique and biologically significant membrane proteins by x-ray diffraction, nuclear magnetic resonance (NMR), electron microscopic, mass spectrometry, and other biophysical techniques are encouraged. Projects that will lead in the near term to determining the structures of biologically important membrane proteins are also encouraged.



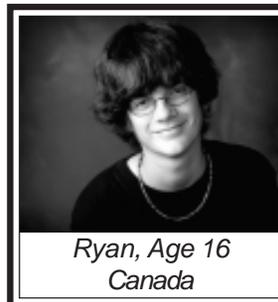
*Benjamin, Age 3  
Texas, US*



*Alfie, Age 7  
Scotland*



*Ben, Age 13  
South Africa*



*Ryan, Age 16  
Canada*



*Chris, Age 21  
Michigan, US*

## 'Faces' of Barth syndrome

## Pilot and Feasibility Clinical Research Grants in Diabetes, Endocrine and Metabolic Disease (R21) PA-06-387

**Purpose:** To support short-term clinical pilot studies and planning activities to help stimulate the translation of promising research developments from the laboratory into clinical practice for diabetes, endocrine and metabolic diseases.

## Application of Metabolomics for Translational and Biological Research (R01) PA-07-301 (and the R21 version for pilot/exploratory projects: PA-07-302)

**Purpose:** To promote the application of metabolomic technologies for translational research in human health and disease to enable/improve disease detection, diagnosis, risk assessment, prognosis, and prediction of therapeutic responses.

## Diet Composition and Energy Balance (R01) PA-07-218

**Purpose:** To investigate the role of diet composition in energy balance, including studies in both animals and humans. Both short- and longer-term studies are encouraged, ranging from basic studies investigating the impact of micro- or macronutrient composition on appetite, metabolism, and energy expenditure through clinical studies evaluating the efficacy of diets differing in micro- or macronutrient composition, absorption, dietary variety, or energy density for weight loss or weight maintenance.

## Chronic Illness Self-Management in Children and Adolescents (R01) PA-07-097 (and the R21 version for pilot/exploratory projects: PA-07-099 and the R03 version for small research grants: PA-07-098)

**Purpose:** To improve self-management and quality of life in children and adolescents with chronic illnesses. Children diagnosed with a chronic illness and their families have a long-term responsibility for self-management. The child with the chronic illness will have a life-long responsibility to maintain and promote health and prevent complications. Research related to biological/technological factors, as well as sociocultural, environmental, and behavioral mechanisms that contribute to successful and ongoing self-management of chronic illnesses in children is also encouraged. This is restricted to studies of chronic illnesses in children and adolescents ages 8 to 21 grouped by developmental stages according to the discretion of the investigator.

# Barth Syndrome Foundation of Canada

## Working together in many directions

By Lynn Elwood, President, Barth Syndrome Foundation of Canada

Whenever we put an update together we're amazed at how much there is to share. Even with the quieter summer months, there has been a lot of progress within the Canadian organization since the last newsletter, and of course we continue to work closely with the international organization. Here is a summary of some of our activities.

### AWARENESS AND CONFERENCES

We have had booths at two scientific/medical conferences this year. The most recent was the Child Neurology Society Conference in Quebec City. This was a very successful conference with a number of physicians, some known to us and some new, coming by the booth to gather information. In conjunction with this conference, Cathy Ritter and Chris Hope made a visit to the Montreal Children's Hospital of the McGill University Health Centre where they shared information with Cardiology and other departments. It is often hard to know whether physicians receive and read the material we leave or send. In this case, we have already found out that the information left there was read by cardiologists in Montreal.

We continue to have advertisements published regularly in the Medical Post and thank them for their continued assistance.

### Banners — A creative new design

This year we had banners and a booth backdrop designed and made for us. They are beautiful and very portable. We have already displayed them at the CNS Conference in Quebec and at a volunteer workshop, and expect to make use of them often. Thanks to Sam Hamilton for his creative design work on these, and to Lois Galbraith and Chris Hope for managing this project.

### FAMILIES AND VOLUNTEERS

Since our latest family Outreach gathering in April we have been in regular contact with most of our families. We are looking forward to seeing all of you at the 2008 International Conference.

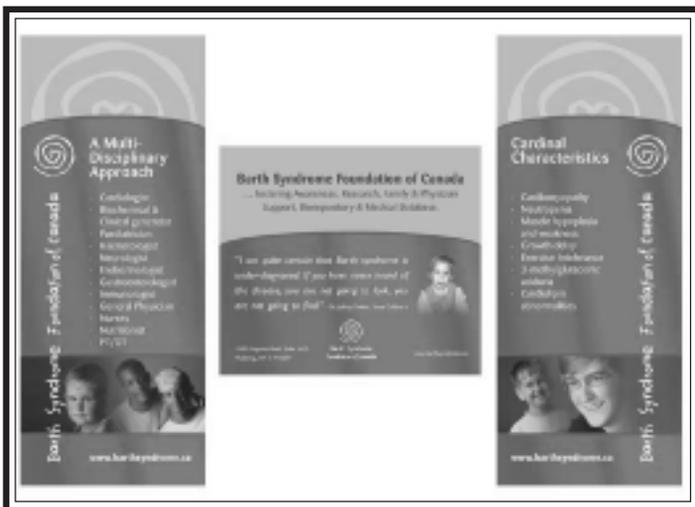
Final touches are being put on a set of fact sheets that will be packaged and sent out to families to assist in daily issues related to Barth syndrome. That is expected to be sent out early in the New Year, along with an updated Healthcare Professional brochure.

We have again been fortunate to have an active and eager group of volunteers who have helped in virtually every program area. Their enthusiasm is infectious and we love working with the expanded group. See the article on page 11 for details.

### FINANCES AND FUNDRAISING

Our finances continue to be in good shape as our fundraising and donations have gone well in 2007. Our annual mail campaign was more successful than 2006, as was our 'Change for Barth' program. At the time of writing we are about to take delivery of poinsettias for the annual seasonal fundraising program, which is also going well.

The Third Annual Golf Tournament at Tangle Creek was a great success again. This is our largest fundraising event and raised over \$20,000. We had more golfers, many hole sponsors, and more raffle prizes than ever. There was even a cruise to be won through the choice of numbered golf balls. It was amazing to watch the set of volunteers put together such an organized and well run day, while making it so warm and friendly that even the Golf Club looks forward to having us return. Thank you to everyone that made this great day happen.



(Cont'd from page 18)

## SCIENCE AND MEDICINE

We are now entering into our planning phase for 2008. With the financial success of 2007, we expect to participate in scientific grant funding again in 2008, if there is a suitable grant application after review by the international Scientific and Medical Advisory Board. We will have more news to share on this and the other 2008 plans early in the New Year.

## RAISING AWARENESS AND HELPING GET TO THE CONFERENCE

Back at the first Barth conference, Susan Hone wanted to be able to bring her family and was able to do that partly through the generosity of her friend donating air miles to her. This year Susan submitted the story about her friend's generosity and their desire to reach the 2008 Conference to the Air Miles for Everyone competition. The Public voted on a website which hosted the stories and Susan was chosen as the grand prize winner of 15,000 air miles, from 10,000 national entries.

Several of us have been on-line voting trying to help Susan win the contest, but Susan went even further. She spoke to the local paper which then ran an article, picturing Susan and Jared, about Barth syndrome and the work the affiliates are doing around the world. We congratulate Susan on her success in the competition and thank her for the awareness she has raised through the contest!

## INTERNATIONAL BARTH CONFERENCE

We're looking forward to the 2008 International Conference in Clearwater, Florida. This is a great opportunity to introduce physicians and scientists to other professionals associated with Barth syndrome, and to have them see several affected individuals and their families. It is also a great chance for volunteers to help out in a different way and to meet the incredible people associated with this Conference and the Foundation.

We recently sent out a brochure about the Conference to all families and professionals on our mailing list. If you would like more brochures to spread information about the Conference to your family, physicians or other contacts, please let us know.

Thank you once again to all of our **Friends of Barth**. Many of you are listed in the back of this newsletter and we appreciate all you have done to help us in time, advice and donations. For those whose names we may have missed, we apologize and would appreciate hearing from you so we can update our list. It takes each of you to keep the organization and programs running and we appreciate every one of you. Thank you!



After tabulating more than 300,000 votes, the people have spoken and chosen Susan from Saskatchewan and her AIR MILES Memory as their favourite. Congratulations to Susan and Jared (age 14).

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“ I just wanted to say a great big thank you to everyone who has been voting for me in the air miles contest.

I am always surprised by the dedication and willingness of this group to help out with anything, anytime, no matter what it is.

I am the grand prize winner of 15,000 air miles, but I couldn't have done it without everyone's help.”

~ Susan Hone

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# Creative ideas to raise awareness of 'Barth' Newlyweds and 'Friends of Barth'



Marj Sawh eagerly attended our first Canadian Volunteer Workshop and has become an avid supporter and volunteer. She has planned fundraisers and spread awareness in her Respiriology Therapist classes for some time now. She is always thinking about Barth and how better to spread the word amongst her colleagues!

This summer, on their wedding day, Brian and Marj once again were thinking about Barth syndrome and made it a special part of their day. They placed an envelope at each place setting at their dinner, and in the envelope was a Barth Syndrome Foundation of Canada awareness card, along with the following note:

*To Our Family and Friends,*

*We are truly blessed by how God has brought us together. We feel fortunate to have you here with us to share in this very special day. In lieu of a traditional wedding favour, we have made a donation in your honour to the Barth Syndrome*

*Foundation of Canada, a cause that is very near and dear to our hearts. Their mission is to guide the search for a cure, to educate and support physicians, and to foster an informed and caring community for affected families. Thank you for your continued love and support. God Bless. ~ Brian and Marjorie Bridger*

How unbelievable it is that such a young couple, with no familial tie to Barth syndrome, would be so unselfish and dedicated and so willing to share their wedding day with our cause! We wish Marj and Brian a very happy future together.



## Barth Trust of South Africa Year ending 2007

*By Jeannette Thorpe, Chair, Barth Trust of South Africa*

It is my pleasure to introduce Carol Jardine who joined the Barth Trust of South Africa as a Trustee at the beginning of the year.

Carol has known our Barth child, Ben, for some years. Her youngest son, Callum and Ben have been at school together since Grade 0. Carol and her family have observed the many ups and downs that Ben has experienced over the years due to Barth syndrome. She was delighted to accept the position of Trustee in order to assist us on our journey to find a cure for all who are affected by this disorder.

She began her career at the forefront of the IT age. Carol stopped full-time employment to start her family, but this did not stop her enquiring mind and busy fingers. What started as a hobby (the creation of designer hobby horses), grew into a thriving and successful business, known as GAJ Nags. Over the years the business changed to meet the demands of its customers: gift card creation, machine embroidery, photography and desktop publishing. Her customer base spans small entrepreneurs, home users, the corporate market and schools.



Carol was very involved in my first fundraiser for the Barth Trust of South Africa and did all the print and design work for the invitations, menu, race cards and thank you cards. This particular job required a lot of "outside the box" thinking, and she embraced it with both hands. I am sure I gave her a few sleepless nights, but the results were spectacular, to say the least! Needless to say, Carol's work ethic is amazing; she is highly creative, intelligent and efficient beyond words. We are very lucky and privileged to have her on our Board. Thank you Carol!

I am delighted to announce that Drs. Harrisberg and De Decker will be joining us again at the Conference in 2008. They are both looking forward to learning the latest updates about Barth syndrome and spending time with all those they met in 2006. Thank you, Doctors, for embarking on this long trip again. Hopefully the ride will be smoother this time!



# Sibling spotlight

## Featuring friends from around the globe

By Alanna Layton, Sister of Barth Individual

**B**elow are the profiles of three of our fantastic 'Barth siblings'. It is wonderful to see siblings of those affected with Barth syndrome form new friendships among our community of 'Barth Families.' We strongly believe that these relationships are so meaningful and will be everlasting!



**Name:** Ellie

**Age:** 11

**Where do you live?:** England

**What are your hobbies?** Horse riding and dancing.

**Affected sibling:** Ollie

**What is your favorite thing to do with your brother?** I enjoy playing on the Wii, especially Wii Sports. I also like playing cards with him, oh and arguing!

**If you met someone who just found out that their brother had Barth syndrome, what would you say to them that might make them feel better?:** Having a brother with Barth syndrome can be frustrating, especially when they have to spend time in the hospital, but you meet such nice people as well and do great things with the BST.

**What does BSF/BST mean to you?:** BST is a community where I meet other families who understand what having a brother with Barth syndrome is like.

*Ellie is pictured above with her brother and sister.*



**Name:** Shannon

**Age:** 14

**Where do you live?:** Canada

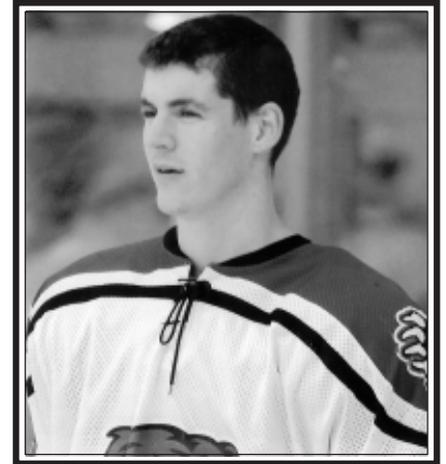
**What are your hobbies?:** Playing guitar, hanging out with my friends and listening to music.

**Affected sibling:** Travis

**What is your favorite thing to do with your brother?:** Going to the skate park together.

**If you met someone who just found out that their brother had Barth syndrome, what would you say to them that might make them feel better?:** I would tell them that my brother has Barth syndrome too, and that it's not always so bad because my brother does pretty well and some of the other boys do well too.

**What does BSF/BSF of Canada mean to you?:** My brother has Barth syndrome and BSF gives the families a lot of support.



**Name:** Mike

**Age:** 23

**Where do you live?:** Brockton, MA, US

**What are your hobbies?:** Playing hockey, work and school. I also hope to coach hockey some day.

**Affected sibling:** Tim

**What is your favorite thing to do with your brother?:** Playing video games and going shopping.

**If you met someone who just found out that their brother had Barth syndrome, what would you say to them that might make them feel better?:** I would just talk to them about the Foundation and tell them about how many people we have watched grow over the years. The diagnosis might have been pretty bleak at first, but we've watched a lot of people with Barth syndrome continue to grow up, so there really is hope.

**What does BSF mean to you?:** I've noticed that with my parents and Tim, the support from the group has been huge for them, something they can lean on. And the support spills over to the siblings as well. We have friends for life now and have been able to get a wealth of information about the disorder.

# Pushing Barth syndrome research forward

## SMAB meeting in NYC generates new ideas about disease mechanism and potential treatment options

By Matthew J. Toth, PhD, BSF Science Director; BSF Affiliates' Scientific Advisor



*“...There are many feasible paths towards finding an effective treatment for Barth syndrome. Many of the attendees at this meeting are actively engaged in that pursuit. However, there is always a need for more talented researchers and clinicians to pursue these ideas and find out if/how they can be realized.”*

*~ Matthew J. Toth, PhD*

**O**n July 10, 2007 Matt Toth, PhD, BSF Science Director, met with members of our international Scientific and Medical Advisory Board (SMAB) and selected others in New York City, to determine what science is needed now in order to push for more research in the direction toward a treatment for Barth syndrome. This was the first such scientific meeting held in a year when we do not host an international conference.

Participants of this meeting included the following members of BSF's SMAB: Richard Kelley, MD, PhD; Barry Byrne, MD, PhD; Gerry Cox, MD, PhD; Iris Gonzalez, PhD; Miriam Greenberg, PhD; Michael Schlame, MD; Matt Toth, PhD and Kate McCurdy. Mindong Ren, PhD, Assistant Professor, Department of Cell Biology, New York University School of Medicine and Matthew Sills, PhD, Executive Director, Pre-Clinical Development, Pharmacopeia, Inc. also attended.

### OVERVIEW

This meeting agenda ranged over many topics of Barth syndrome (BTHS) research, updated the attendees on new data, and suggested new ideas about disease mechanism and potential treatment options.

### Exon 5 patients

The presence of near normal amounts of cardiolipin in the two Barth syndrome patients with identical exon 5 mutations suggests that dysfunction of this lipid may be indicative, but perhaps not causative, of the many symptoms BTHS patients endure. The importance of exon 5 in the tafazzin protein of higher primates continues to be a mystery, and the need for a rigorous cell culture system, as well as a mouse model of disease, was apparent. There are at least two competing theories to explain the pathophysiology of BTHS: mitochondrial energy dysfunction or mitochondrial protein import dysfunction. While it appears solid that the monolysocardiolipin/cardiolipin lipid ratio is diagnostic of Barth syndrome, the mechanism by

which symptoms appear is still elusive. The mitochondrial energy hypothesis is supported by the dysfunction of OX-PHOS in tafazzin deficient cells, and can be tested clinically by measuring the exercising muscle of BTHS patients. The mitochondrial protein import hypothesis is supported by the symptoms suffered by patients with the recessive Barth-like syndrome — a disease with mutations in the homolog (DNAJC19) of a component of the yeast mitochondrial protein import machinery (Tim14).

### Research

There are several tools that are still wanting in BTHS research, though solutions to these voids are now being actively pursued:

- mouse (or mammalian) model of tafazzin deletion
- antibodies that can identify endogenous (low) levels of human tafazzin protein
- cell culture system where different mutants of tafazzin can be expressed and analyzed in a relevant cell type
- high-throughput assay that measures the enzymatic activity of tafazzin
- more simple assays that can measure the many aspects of mitochondrial function and an accurate incidence rate for BTHS

### Potential Therapeutic Treatments

Potential therapeutic treatments for Barth syndrome were also discussed at length. Most of these ideas will require more investigation before any contemplation of a therapy. When a therapy is to be clinically tested, the lowering of fatigue may be the quickest indicator of effectiveness.

**IN CONCLUSION**, there are many feasible paths towards finding an effective treatment for Barth syndrome. Many of the attendees at this meeting are actively engaged in that pursuit. However, there is always a need for more talented researchers and clinicians to pursue these ideas and find out if/how they can be realized.



# Clinical and basic science researchers unite

## Exploring new ways to further Barth syndrome research

By Carolyn Spencer, MD, Assistant Professor Pediatrics, Department of Cardiology, Children's Hospital, Boston, MA;  
Co-Principal Investigator, Barth Syndrome Registry and DNA Bank at the University of Florida

**The Barth Syndrome Foundation (BSF), along with clinical and basic science researchers, have united to explore ways to further research into Barth syndrome.**

The BSF and researchers based at the University of Florida (UF) recognized the difficulty in investigating a rare disease at a single institution due to the low number of patients under the care of any one single physician. With the collection of medical data and DNA from Barth syndrome patients from across the world, a broad spectrum of medical data linked to genetic data may be collected. The aims of the Registry and DNA Bank are to better understand the natural history of Barth syndrome using historical and current information obtained via the Registry. Additionally, the Registry aims to enhance research by developing a tissue and DNA bank that can be used to better understand the cellular basis for the disease and to link this information to the medical outcomes and natural history through the Registry.

### Medical Data

The medical data portion of the Registry is being developed by the Institute for Child Health Policy (IHP) at UF. The Registry database is a secure database with access only by the IHP staff, UF Principal Investigator and their staff. The DNA is banked at UF and the lymphoblast lines are developed and stored at Johns Hopkins Cell Center in the Genetic Resources Core Facility. The Registry medical information and DNA/cells in the bank are linked via subject code only, and samples are labeled with the barcode specific to the patient.

Two types of medical information are collected for each individual enrolled in the Registry. One type of information is provided by the family (demographic information, family history, basic medical

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**“The aims of the Registry and DNA Bank are to better understand the natural history of Barth syndrome using historical and current information obtained via the Registry.**

**... enhance research by developing a tissue and DNA bank that can be used to better understand the cellular basis for the disease and to link this information to the medical outcomes and natural history through the Registry.”**

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history, etc.) and the other is collected through medical records (medical or laboratory testing results, specific hospitalization information, etc.). At the time of enrollment, each patient (or his parents) signs an informed consent form, completes the Registry enrollment questionnaire, and signs a release of medical information to allow the Registry to obtain the specific medical records. Many families have provided the medical records directly to the Registry to facilitate collection of the medical data.

### Patient Enrollment

Patients may enroll in the Registry and provide medical information data without providing a blood sample for DNA. At the time of enrollment in the Registry or shortly thereafter, those who also wish to participate in the DNA bank portion of the Registry provide a blood sample. This blood sample allows for the collection of DNA and the development of cell lines linked to the medical information. A blood drawing/shipping kit is provided by the Registry to allow blood to be drawn and shipped from the local hospital or lab to the Registry.

### Research

Researchers with approval from both their local institutions and the Registry Medical Advisory Board may request data and/or DNA or cell lines. Only “anonymized” information is released to researchers (i.e. all released information is coded).

Examples of possible research that could utilize the Registry and DNA bank may include an investigator who wishes to evaluate differences in genes from patients with severe neutropenia versus those who have had mild or no neutropenia. Another researcher may wish to evaluate differences in modifying genes in those with heart failure requiring transplantation versus those with mild or no heart failure.

Currently there are 42 individuals with completed enrollment information, along with 27 samples in the DNA bank and 24 sets of lymphoblast cell lines.

More information as well as enrollment forms can be found on the Barth Syndrome Registry and DNA Bank website at:

[www.peds.ufl.edu/barthsyndromeregistry](http://www.peds.ufl.edu/barthsyndromeregistry)  
or e-mail: [barthregistry@peds.ufl.edu](mailto:barthregistry@peds.ufl.edu).



# At the forefront with other rare disease groups

By Shelley Bowen, BSF President; Kate McCurdy, BSF Board Member; Michaela Damin, Chair, Barth Syndrome Trust

Recently I was asked, "What was the pivotal moment when the Barth Syndrome Foundation (BSF) transformed from a fledgling charity into a trailblazer within the health advocacy sub-sector?" I hadn't realized that we were now being looked upon as a 'trailblazer'.

My questioner explained, "BSF has become a standard to benchmark for best practice in the rare disease community. At what point did you know that you were going to be successful?" That was easy, "We planned for success; failure was never an option for us. Our boys deserve the best and we give our best. When our best is not good enough we acknowledge it and get someone else to help us. It is not our job to do it all, but it is our duty to make a difference."

What makes us unique is our culture of community, connectedness and collaboration. One of BSF's more visible signs of collaboration is our involvement in rare disease efforts beyond Barth syndrome. While we do not want to dilute our focus, it is essential to have a constructive voice in the broader rare disease community and also to gain knowledge that we can apply to our own mission. The following examples give you a flavor of what we are achieving.

## USA

Collaboration, Education and Test Translation (CETT) is a national program that facilitates the translation of genetic tests for rare diseases from research settings to CLIA-approved laboratories so that the tests are readily available and the results can be used for diagnosis and treatment. Historically this process could be cumbersome and/or difficult, so the Office of Rare Diseases (ORD) of the National Institutes of Health (NIH), along with other organizations including the Centers for Disease Control and Prevention (CDC) and a number of professional Genetics Societies, developed the CETT program which

provides funding as well as a new model of best practice. In addition, new standards for educational materials, clinical data collection and test reporting are evolving from this on-going process.

Kate McCurdy, a BSF Board member, has been active in the development of this program since 2005 and has served on one of the three application Review Boards since its inception. Using her experiences as the mother of a son with Barth syndrome and her medical knowledge, Kate has been able to provide a perspective of patient advocacy, one that plays an important role throughout the CETT program. To illustrate, applications to support rare disease test translation under CETT must be submitted by a collaborative group, consisting of a clinical laboratory, a researcher, an expert clinician, and a patient advocate. The proposals are then passed on for evaluation to a Review Board consisting of a clinical geneticist, a laboratory geneticist, a research scientist, a health care provider, a biochemical geneticist, and, again, a patient advocate. The patient advocate brings essential knowledge, experience and value to this process. Kate is honored to have been a part of this important national program. In the process of helping other rare diseases, she has spread awareness of Barth syndrome, made important contacts and learned a great deal that is very useful in advancing our own specific disorder.

## UK and Europe

*Partnering with the European Organisation for Rare Diseases (EURORDIS) and the Genetic Interest Group (GIG) in the Rare Disease Patient Solidarity Project (RAPSODY)*

People with a rare disorder like Barth syndrome spend much of their time going from one appointment to another. Complex disorders need a number of medical professionals, each one taking on a small piece of this puzzle, each one

usually working in isolation. So families in the UK and Europe are requesting a new model of care for rare disorders including a centre of expertise. The centre is one place where all the necessary specialists are present; a place to meet other affected families; a place which fosters learning and communication and a place which leads to better care and increased knowledge about the condition.

The Barth Syndrome Trust (BST) took part in a national UK workshop in March 2007, together with other patient groups, health care professionals and policy makers. The aim was to formalise a UK perspective on the needs and expectations of patients and families for centres of expertise in preparation for the European conference.

Michaela Damin from BST was chosen by GIG to represent the UK at the European EURORDIS conference in Prague in July 2007. The conference discussed the establishment of centres of expertise. Speakers included the European Union High Level Group on Health Services and Medical Care, Alpha 1 Network (EU funded), Orphanet, Cystic Fibrosis European Network and the Genetic Interest Group.

The movement to create centres of expertise for rare disorders is gathering momentum across Europe. BST, together with key organisations and committed people, is playing an important role in ensuring that families affected by Barth syndrome get the best care available.

## The future

Our experience increasingly shows the benefits of patient advocacy and collaboration. We need to join forces with other like-minded groups to ensure a brighter future for all those affected by a rare condition.



# BSF Northeastern Outreach

## Proclamation of “Barth Syndrome Awareness Weekend”



Forty-one family members (including ten Barth individuals) and three medical sub-specialists with expertise in Barth syndrome gathered for BSF's Northeast Outreach in Brockton, MA on August 17-19, 2007.

On August 17th – 19th, nearly fifty BSF family members joined the Monahan and Dunn friends and families in a weekend of fun in their hometowns. On this occasion, friendships multiplied as we came together for one extraordinary weekend of fellowship.

The Brockton Enterprise featured the event on the front page of the newspaper. WXBR, a local radio station, which airs a live feed over the Internet promoted awareness about Barth

### Northeast Family Outreach August 17th – 19th, 2007

By Shelley Bowen, BSF President

That first e-mail we sent to contact someone about Barth syndrome is the one that the majority of us recollect with great vivid clarity. This e-mail was unique from the thousands of e-mails we had ever sent before that moment or since. It was a quest for knowledge arising from our concern about someone we care about very deeply. We couldn't have known the difference that e-mail would make in our lives when we first reached out to someone over the Internet. I hunch we can all recall that first e-mail — where we were sitting, what prompted us to send it, and wondering when we would hear back from a stranger on the other end of the wire. In most cases the first e-mail from a family is a modern day S.O.S. We anxiously awaited a response from our S.O.S. However the compassionate community we immediately became a part of extended far beyond our expectations.

It seems odd to say that we have fun when we are together but perhaps that is what distinguishes us from other groups. Last spring, I called Anna Dunn and asked her if she would be willing to help me organize a family gathering in the Northeast. At that time we didn't know that the Three Musketeers (Tom Monahan, John Higgins and Mark Dunn) were already making plans of their own. So, I asked if we could all join them. John said, “*We have fun when we get together so we make an effort to do it as often as we possibly can. It would be great if more people could come. The more the merrier.*” The day after Tom and I had discussed ideas for the weekend he pretty much had everything arranged.

syndrome. By formal proclamation, Mayor James Harrington declared August 17th – 19th, Barth Syndrome Awareness Weekend in Brockton, MA.

During the educational sessions, Renee Margossian, MD, Assistant in Cardiology, Children's Hospital Boston addressed cardiac aspects of Barth syndrome. Our SMAB board member Gerald Cox, MD provided a retrospective of how far we have come since his first experience in treating children with Barth syndrome. He also gave his views about the opportunities from BSF-funded research grants and the Barth Syndrome Medical Database and BioRepository to facilitate research. Matt Toth, PhD, BSF Science Director discussed recent research and new frontiers.

Friends and family members of the Monahan and Dunn families joined us throughout the weekend. Tom's cousin Bill traveled over 3,000 miles to join us for the event. On Friday evening we had the opportunity to thank the Monahans' and Dunns' friends and families for their support. On Saturday Tom taught me how to pitch a baseball in his backyard in preparation for my pitching the first ball of the Brockton Rox game which everyone attended that evening. And I did it!

On the last day Anna and Mark Dunn welcomed us to their home and introduced us to their family and friends. It was a beautiful sunny day for this family picnic and we all enjoyed the live entertainment provided by Mark's friends. The music, food and fellowship were awesome. By the end of the weekend we were all exhausted. We could always sleep but we couldn't always be together. So, we squeezed every precious moment we could out of the weekend.



# A community that impacts and supports many lives

## Barth syndrome is the bond that keeps us together



**W**hat is it like to be the father of a young man with Barth syndrome? What type of support have you gained from being involved with the Barth syndrome community?

**“A friend is someone that knows you as you are, understands where you have been, accepts what you’ve become, and still allows you to grow.”**

I’d like to begin by saying that I consider Tom Monahan and Mark Dunn more than just my dear friends, they are more like brothers. In a sense, we really are brothers in the bigger family that we refer to as “Barth”.

**Mahatma Gandhi said, “If I had no sense of humor, I would long ago have committed suicide.”**

The very first time that I met both Tom and Mark, I could see that we shared something that I’ve always felt was probably the most important thing in life... a sense of humor. In fact, it appears that all of the Barth families have a great sense of humor. It comes with the territory.

**Solidarity is defined as, “union or fellowship arising from common responsibilities, interests or sympathies”.**

We have all stood in each other’s shoes (like when learning of our son’s illness). We can feel each other’s pain. We immediately identified with each other and seemed to think a lot alike. I could see that they both clearly loved their children and adored their wives. The attitude within the Higgins family unit is, “One for all and all for one”, (with the exception of our teenage daughter, Kelsey, who is more like, “All for me and me for me”, but that’s a story for another time). I believe Tom’s and Mark’s families share the same feelings.

Not a week goes by without the three of us touching base with each other about something specific or just to “shoot the breeze” about everything and about nothing. It’s a wonderful feeling knowing that they are both just a telephone call away.

There isn’t anything I wouldn’t do for either one of them...except, of course, root for the Red Sox, Patriots, Celtics or Bruins. ~ *John Higgins, New Jersey*

**Where do I begin?** Well let us see. We have grown very fond of the Dunn and Higgins families over the years and it has nothing to do with the fathers in this trio of Barth families. The mothers are really the glue that keeps the families together and sane. These women are just unbelievable and really have more guts and determination than the three amigos could ever have dealing with this disease (brownie points). They are all extremely smart and up to date on all the latest information on the disease and strong advocates for their boys.

Having known John and Mark over these many years of dealing with Barth syndrome has been a great help to my sanity (not that I had much to begin with). I actually love these guys and have a lot of fun with them. I hear from both of them every week. I will get a call from John or Mark at any time during the workday (obviously these people need to get a job) and have a few laughs. We talk about sports and families of course, but mostly about sports and anything else that we can harass each other about. We try to get together with our families as much as we can. Mark lives only 40 minutes away and so we see them quite often. We try to go to the Higgins’ fund raiser in the hills of New Jersey each year. The families enjoy the trips and love getting together.

These relationships started because of the disease our boys suffer from. As awful as this disease is, the one good thing that has come out of it is the opportunity to meet and form relationships with other families going through the same problems and situations as we are. In addition to supporting each other, great friendships and support have been formed.

Our relationships with each other are helped by the fact that we live close to each other. In addition, the relationships we have with all the other families we have met over the years are awesome and very helpful. Every family has opened their homes and hearts to us. The bond we have with them has made life so much easier to deal with. We visited the Manns when our son was playing hockey against the University of Tennessee last year and they treated us like family, just to name one example.

In closing, I would like to say to all the new families that being involved in the Foundation and being involved with other families, by e-mail, phone or actually visiting each other is what will keep you going. Knowing you don’t have to go through this alone, that we are there for each other fighting together to beat this disease, is what this Foundation is all about. Be a part of it. ~ *Tom Monahan, Massachusetts*





## DUTCH SPEAKING FAMILY GATHERING Belgium – 2 September 2007

By Annick Manton, BST Family Services

In September, I attended a Family Gathering in Belgium as a representative of the Barth Syndrome Trust (BST). It was an excellent and productive weekend packed with activities for the Dutch speaking Barth families. They are indeed a great, friendly group of people who made me feel very welcome. Veerle and Erik graciously received me into their home with warmth and kindness. I enjoyed spending time with them and their delightful young boys.

The Gathering took place at the Domain of Bokrijk – 550 hectares full of peace, adventure, greenery, animation and culture. The children had great fun in an enormous playground. We went for pleasant walks and we visited the amazing Open Air Museum, a collection of old Flemish houses and farms. Veerle organised the day efficiently ensuring that we were always together as a group. She also provided a delicious lunch with drinks and snacks all day, as her family's contribution to BST. All the families present went home exhausted but very happy with their day. Ouma Annick could hardly walk at the end of the busy day and should have taken a three wheeler to keep up!

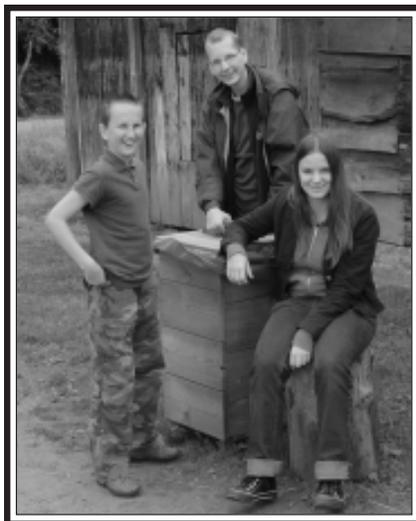
My objectives as the leader of BST Family Services were to get to know the European families, find out what their needs, wishes and expectations were and, hopefully, forge stronger relationships. I also wished to share our initiatives and learn more about their perspectives. On behalf of Michaela and BST, I passed on all information about the Medical Database and BioBank. The families were keen to participate in this project.

During the day I spent time with everyone getting to know them all. I was particularly pleased to meet Johan. He has been quietly and efficiently supporting our Dutch speaking families since he took over from Jo this year and has become a valuable member of our Family Services team. I

was also able to communicate with grandparents, parents, young adults, boys, and siblings in spite of my lack of Dutch. I tried to answer their numerous questions and we talked about the many Barth related difficulties as well as blessings that we shared, such as the daily struggles of our boys, their tenacity and courage and their many achievements.

All the Dutch and Belgian families truly enjoy these annual social gatherings and they intend to continue to meet regularly. Most of them are presently doing very well and coping with daily life. Like most affected families around the world, they consciously try not to make Barth syndrome the centre of their lives.

It was amazing to meet two adult men with Barth syndrome. Both are married with children. Their daily lives are very different. One is not affected severely and manages to work 12 to 14 hours a day whilst the other is challenged with limited stamina. Regardless of their different experiences with the disorder, neither of them allows Barth syndrome to define their lives.



I also spoke to a young man who is coping well at university and enjoying living away from home during the week. He feels that he is doing more now that he has to be independent. His mother is very proud of her son, for as "normal" as this accomplishment may be for a healthy young man, it is particularly inspiring for someone with Barth syndrome. These "old timers" are also an inspiration to the newly diagnosed families. A grateful mother explained how meeting them inspired her teenage son. As a grandmother, I particularly enjoyed meeting other grandparents. There was mutual empathy and complete understanding as we shared our experiences. I learned about the challenges of families from a previous generation, their heartbreaking losses and their helplessness as they did not know what they were facing.

It was indeed a pleasure and a privilege meeting our Dutch and European families. It allowed us to establish a rapport and break down the barriers that isolate us in our respective countries. As we pool our resources, we will be able to work better as a global organisation and live up to our motto... *"Saving lives through education, advances in treatment and pursuit of a cure"*.

### A note from Veerle

"As it was my first time, I was nervous about the organisation of a BST family gathering. But with the enthusiastic help of my sister-in-law, I became really determined to make a beautiful day of it. And it worked! We had the serious moments about the medical issues, but we also had a LOT of fun together! I was also very happy to have Annick, 'the English woman' as our boys constantly called her, staying over in our home. I admire her for doing this trip alone and she informed us so well about everything that is going on in BST. Like all of us, I try not to let Barth syndrome control our lives, but we are very grateful for what BST/BSF are doing. As we all understand each other in a way no one else does, I think we should stay closely in contact and share our experiences in order to help our boys."



Photo: Justin (15), Peter (20) and Laura (16).

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Microsoft Matching Gifts Program  
Mike Erdman Motors, Inc.  
Miller, Gary/Cornelia  
Miller, Jill  
Millman, Paul/Suzie  
Mills, Kevin/Nanci  
Mills, PA, Leyanys (Neighborhood Health and Wellness Center)  
Minor, Walter  
Mirabile, Saverio/Jeanette  
Mixter, Stephen/Elizabeth  
Moed, Andrew/Kim (Symach Holdings LLC)  
Moncure, John  
Monetti, John/Rejane  
Monetti, Tim/Cathy  
Montanaro, Louis/Theresa  
Morehouse, III, L.Clark/Susan  
Morris, Antoinette/Ramon  
Morris, Les  
Mosley, Daniel/Heather  
Motzkin, Robert  
Mueller, Carl/Suzanne  
Mueller, Henry  
Murphy, Donald/Jane  
Murphy, John  
Myers, Judith  
Nachman, David  
Nadler, Jeffrey/Joanna  
Nauheim, Dr. J.S./Mae  
Nelson Engineering Company  
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Newfield, Jeff/Beth  
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Nichols, Chris/Bill  
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Northrup, Bruce/Jan  
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O'Connor, Mary  
O'Donnell, Terry  
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Orlich, Charles  
Osterberg, Kristin  
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Pare', Jaclyn  
Parent, Kimberly Trowbridge  
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PCCL  
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Pratofiorito, Anthony  
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Protenis, Paul  
Prudential Wexford Realty  
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Putnam Investments  
Quentin L. Hampton Assoc. Inc.  
Raab, Sheldon/Judith  
Rabinowitz, Stephen  
Ragusa, Thomas  
Randell, Dr. Jay/Amer  
Randolph, Gregory  
Ranish, Dr. Melvyn/Carol  
Ratner, Carol/Ian  
Real Time Lead Generation  
Reid, Colin  
Reise, Alyssa/Jack  
Reynolds, Smith and Hills, Inc.  
Rhatigan, Joyce/Michael  
Rich, Dr. Richard (Shelter Rock Orthopedic Group, P.C.)  
Richman, Dr. Daniel  
Riera, Richard  
Rigney, John  
Rivers, Angelina  
Rivers, Ray (The Rivers Family Foundation, Inc.)  
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Roberts, John/Elizabeth  
Robertson, Harriet  
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Rodbell, Gary/Colette  
Rodbell, Mitchell/Elizabeth  
Roden, Scott  
Rogers, Dawn Divenere  
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Segal, Heather  
Segal, Joe  
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Smith, Jeffrey/Judi  
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Somekh, Edward/Elizabeth  
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Spectralink Corporation  
Spotts, Dr. Jules  
Stalter, Jr., Daniel/Caryn  
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Strauss, Judith  
Strumwasser, Larry/Laura  
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Sullivan, Robert/Maria  
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Symington, Jane  
Symphony Fabrics Corporation  
Tananbaum, Steven/Lisa  
Tanner, Jason  
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Tezel Investments Inc.  
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The Birbaum Foundation  
The Boca Raton Jewish Learning Center  
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The Lord & Taylor Foundation  
The Nelson Foundation  
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Trentham, Charlene M.  
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 Murphy, Tony  
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 Niemeyer, Christine (Ruppshirts)

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 Olson, Adam  
 Olson, Maria/Tom  
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 Segui, Damaris  
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 Smithson, Sarah  
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 Steinberg, Jack  
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## Barth Syndrome Trust (UK & Europe)

### Angels £500+

Genetic Interest Group (GIG)  
 GlaxoSmithKline  
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 Rotary Club, Basingstoke

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 Bull, Sarah & David  
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 Damin, Marco and Michaela  
 European Barth families at 2006 Gathering  
 Fosters Group  
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 Frost, Michael  
 Grant, Alec and Catherine  
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 Sim Racing Ltd, Chandlers Ford  
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### Donate through our website:

You may donate to BSF or any of the international affiliates by going to our website, [www.barthysyndrome.org](http://www.barthysyndrome.org), and clicking on the 'How to Help' button on our home page.

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Many donors are now taking advantage of a "Matching Program" offered by their employer. The employer matches the funds donated by the employee to a charity and provides a convenient method for the employee to donate to a charity of his/her choice.

### 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.



# Power of kindness

(Contributions donated since July 2006)

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Basingstoke Voluntary Services  
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Lindsay, Sue  
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*"...The Third Barth Syndrome Foundation Conference in Florida, USA proved to offer an enthralling window into a complex and enigmatic disorder, which we are only just beginning to understand. The quality and depth of the research to uncover the syndrome's secrets are astounding. More importantly, however, we came to know a group of parents who through enthusiasm, resilience, and hard work, have managed to energize the process of understanding Barth syndrome." ~ Dr. Rik De Decker, Red Cross Children's Hospital, Cape Town, South Africa*

*"The 2006 Conference was a life-changing experience for our entire family. We now feel that we are a part of something so much bigger and more powerful than Barth syndrome itself! We are so thankful for this group and what it has already meant in the life of our son." ~ Floyd Family, Georgia, US*

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