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# Barth Syndrome Journal

Volume 8, Issue 1

Spring 2008

*Saving lives through education, advances in treatment and pursuit of a cure for Barth syndrome*

## Highlights of Interest

- Nine Research Grants Awarded for 2007 Grant Cycle
- 2008 4<sup>th</sup> International Scientific, Medical & Family Conference
- Barth Syndrome Registry and DNA Bank Enters Second Phase

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NATIONAL HEALTH COUNCIL

*The Barth Syndrome Foundation is a proud member of the National Health Council*

## Barth Syndrome Foundation 2007 Research Grants Showcase Increased Barth Syndrome Awareness and Interest

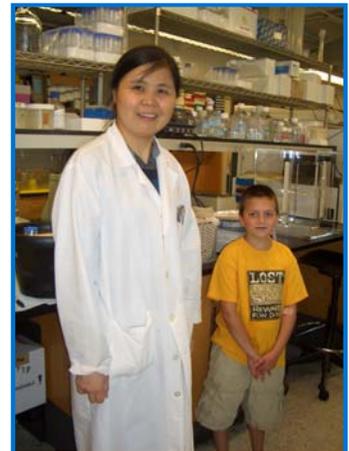
*By Matthew J. Toth, PhD, Science Director, Barth Syndrome Foundation*

The latest cycle of the Barth Syndrome Foundation (BSF) Research Grant Program marks the sixth anniversary of this important funding program with the largest monetary commitment of any previous cycle (over USD \$333,000). Six of the nine awardees have not received funding from BSF before.

The 2007 cycle also received the largest number of grant applications which, along with the increasing numbers of publications and of website hits, demonstrates that Barth syndrome (BTHS) research is becoming better known in the scientific and medical community, as well as to the public.

The nine grant recipients for the 2007 cycle are approaching their research from several different angles. Most of the grants are investigating how tafazzin

*(Continued on page 8)*



*Jack visits Yang Xu, MD, PhD at New York University School of Medicine.*

## Family Sessions of the 4<sup>th</sup> International Scientific, Medical and Family Conference Barth Syndrome: *On Track Toward a Cure*

*By Shelley Bowen, President, Barth Syndrome Foundation*



*Tyler, age 4, invites everyone on board BSF's track toward a cure!*

The Barth Syndrome Foundation's 4<sup>th</sup> International Scientific, Medical and Family Conference provides an opportunity to hear about the latest developments related to Barth syndrome from medical specialists in genetics, hematology, metabolism, neurology and nutrition, to name a few. It is a unique experience for affected individuals, carers, siblings, and anyone who has an interest in Barth syndrome.

As a conference member taking part in the Family sessions, you will not only be brought up to date on medical advances, but the information will be presented in such a way that you can understand it. Parents and all their extended family members have an opportunity to get together and compare

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## Transitions in Our Second Decade

### *From covered wagon to Space Shuttle (but not quite yet)...*

By Shelley Bowen, President, Barth Syndrome Foundation, Inc.



*Michael J. Astrue, Commissioner of the Social Security Administration, with Shelley Bowen at the December 2007 Disability Hearing on Compassionate Allowances.*

**F**or some years now a number of us have said that we feel like 'Barth syndrome pioneers' in a slow covered wagon wanting to take the wheel of a fast-paced Ferrari. In truth we have, but I am not convinced that this Ferrari can anticipate what lies ahead. I am ready to upgrade to a reconnaissance aircraft!

To accelerate the development of our organization for the current and future generations of families, we are seeking an Executive Director. Building the momentum to advance treatment and seek a cure will be the key task of this exciting and challenging job. This transition will allow me to return to the role I first had in the Foundation, to find solutions to the challenges we face.

Our son, Michael, is now 21 years of age. When he first fell ill during his infant years I never dared dream of him being 21. Instead I chose to live one day at a time and not indulge myself with fantasies of the future. You know, those thoughts and aspirations of where your son will go to school, what he will accomplish in life, and so on. There is a virtue of being 'in the moment'. For better or worse, there are limited expectations of what the future may hold.

Our sons are indeed a product of their environment because they, like us, seldom consider what might exist beyond the moment at hand. I am in constant awe over how these boys and young men do their best to find the small pleasures in life despite having Barth syndrome. They may have this disease, but it clearly is not what defines them. Any one of us would take Barth syndrome from a loved one if that were possible. Since that is impossible, we do what is within our power to help him. As much as we would like to take this burden from the person who has it, we are confronted with the hard-cold reality that this is a burden that is his alone to bear.

In recent months it has become apparent that my role as an advocate must be turned over to my son because he is now an adult and must make decisions about his own healthcare. However, those decisions must be made from an informed viewpoint. This is a transition for me just as it is for my son. As these young men are growing into adulthood more parents are going through these transitions. The interesting similarity between parent and child is this: Just as these boys and young men have never known what it is like not to have Barth syndrome, we, as their parents, have never known what it is like not to be their healthcare advocates. It is a unique phase in our lives.

As we prepare for the Conference, I find myself looking forward to it with the same mindset that I looked forward to our very first gathering in 2000. My son is an adult, and I now need, more than ever, that same support network that we first established. We continue to remain pioneers in Barth syndrome but the needs are shifting, and unprecedented barriers now exist. As we move forward into the second decade since many of us first connected with one another, we must focus on these issues.

I recently began to think about the great strides we have made in just one decade. We have created a community from which all of us benefit. As we move forward, we are in a position to accelerate our momentum for Barth syndrome education, research and support efforts. That requires us to look at things from a different perspective. I look forward to what these transitions will bring in the future. I am optimistic and excited about this new phase, but most of all, I am excited to once again be allowed to focus on what I hold dearest to my heart, and that is the Barth syndrome community.



# 2007— A Time for Perspective

By Stephen McCurdy, Chairman & CFO, Barth Syndrome Foundation

Every year at this time, I have the pleasure of summing up our community's accomplishments in the previous year. 2007 again was a year when our dedicated volunteers, faithful contributors, caring physicians and brilliant researchers have created and accomplished much. This article reflects their triumph of progress and hope.

Most of the people on the front lines of these efforts are parents who have a very personal reason for volunteering. But in our determination to create a powerful and permanent ally in the fight to save our children's lives, one thing keeps rising up to distract our attention and challenge our hopes; the fear that we may not do enough, fast enough to save our own child. Fear is a powerful thing. It can be highly motivating. But at times it can also be overwhelming. It can become a black, nauseating, and paralyzing demon in its threat to take from us those whom we love the most... and would gladly give our own lives to protect.

The threat is real, and our instinct is to hide, to focus on the immediate tasks that absorb our time. We try to ignore the demon and hope that it passes over our house. The absence of bad news reassures us that we are safe. After 2006 in which we quietly celebrated that Barth syndrome had not taken a single child, recent months brought the sudden death of Michael Reece in Australia, and serious medical challenges to other families from Australia to Florida, Massachusetts and Utah. Barth syndrome has forced two children to have heart transplants and as I write this, two more are on transplant waiting lists. Others from around the world have been hospitalized with other serious complications of Barth syndrome. We are being starkly reminded that this is still a deadly disorder that threatens each of our affected children and indirectly our extended Barth families.

So where do we find solace, hope and the courage to carry on?

We find it in you; each and every one of you. We find it in the Reece family who must find it in each other. We find it in the families who post their questions and prayers on our family listserv every day. We find it in the thousands of faithful family, friends and supporters who send their hard earned money to help us in the only way they know how. We find it in the caring eyes of the doctors who struggle to make sense of the complicated aspects of this disease about which still too little is known. And we find it in the passion of the scientists working long hours in laboratories hoping to find the clue that will unlock the puzzle that is still Barth syndrome. We find it most strongly in the determination of leaders like Shelley Bowen who despite her own family's challenges has adopted all of us into her family and refuses to leave any of us behind in the fight for our lives.

The Barth Syndrome Foundation is now eight years old and no longer a neophyte as a charity. We have accomplished so much in such a short time. But at our core, all of the people who comprise the Barth syndrome organizations share a simple value. We are a family. We care deeply about each other. We give each other the strength, courage and hope to live, to laugh and to face whatever may come each day, knowing that we are not alone. We will never give up.

And I am more proud of that than of any of our many accomplishments (which I have also proudly listed below!) Thank you. All of you.

## BSF Accomplishments

### Family Services

Led by Sheila Mann and Chris Hope

Family Services finds and cares for our families, giving them the strength, knowledge and tools to care for their own. The latest census shows that BSF has grown to a total of 114 boys/young men around the world, with 11 more

(Continued on page 4)

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## 2007— A Time for Perspective

awaiting a confirmed diagnosis. When new families reach out to BSF, Shelia, Chris and Shelley Bowen are there to welcome and support them. Many of our newer families tell us that they were anxious about contacting us for the first time, not knowing what they would find. Those who do, find a warm voice and a gentle introduction to a new family. In due course, they are introduced to the listserv — our global lifeline on the internet and the place where no question is too small, answers come quickly and everyone understands.

In late 2005, we sought to improve the quality of the listserv by publishing a set of rules governing postings. Usage dropped by more than 50%. After surveying our families we learned that the “rules” made them reluctant to post their questions and thoughts. We immediately rescinded the “rules” and usage of the listserv has nearly returned to its previous levels. We may make mistakes in good faith but we learn quickly!

In 2007, we experimented with webinars, hosting live, interactive sessions with an expert on a particular subject of interest to the families. The pilot was successful and we are planning more such sessions in 2008.

BSF produces fact sheets, brochures and papers written by investigators who have conducted research to address specific issues within our community such as bullying, depression, hospitalizations, life balance and education, just to mention a few. Last year, the Family Services team created binders containing all of these materials and mailed them to each family. Updated periodically, these binders become an invaluable resource for record keeping, information for new family doctors, contact lists, emergency information for baby sitters and extended family alike. And now, we have upgraded our listservs to be able to send documents electronically to all families or physicians who have signed up.

A visit to an emergency room is always a stressful occasion made even more so if the nurses and doctors have never heard of Barth syndrome. Our latest brochure for healthcare professionals, endorsed by clinical

members of our Scientific and Medical Advisory Board and intended for physicians, has been especially well received. It provides a quick and credible source of information that can prove critical in caring for a Barth syndrome patient for the first time. It also serves to encourage the medical staff to consult closely with the parents of the Barth syndrome patient in their care. A copy of this brochure was included in the US edition of this newsletter published in late 2007.

As much as BSF is an internet community, there is nothing like the opportunity to spend time together face-to-face. Our outreach program creates mini-BSF conferences in regions around the country. In August of 2007, the Dunn and Monahan families organized and hosted the BSF Northeastern Outreach event outside of Boston. Over 50 Barth syndrome family members attended along with several physicians and scientists who presented updates on their work and information of use to the families. The Mayor of Brockton declared it *Barth Syndrome Awareness Weekend* and the group spent a terrific weekend attending a Brockton Rox Baseball game on Saturday night and a wonderful family picnic at the Dunn’s on Sunday.

### BSF Conference

*Led by Jan Kugelmann, Dr. Matt Toth, and Shelley Bowen*

Planning for the 2008 Scientific, Medical and Family Conference began as the 2006 Conference was coming to a close. Jan Kugelmann led the search, site visits, selection and booking of the location for this year’s Conference in Clearwater, Florida, assisted by Leslie Buddemeyer and Shelley. Jan, Matt and Shelley have been in full planning and organization mode for over a year, mapping the schedules for the individual tracks for scientists and physicians, parents, affected men and boys and their siblings, confirming acceptance by the distinguished speakers, organizing child care and social activities, and the myriad details that make this Conference the consistently professional and successful event that it always is. There is more to read about the conference elsewhere in this newsletter, and I urge you to attend if at all possible. You will not regret it!

*(Continued on page 5)*

Individuals Associated With The Barth Syndrome Foundation and Affiliates Worldwide										
	Living	Deceased	Pending Diagnosis	Living Individuals By Age in Years						
				0-4	5-9	10-14	15-19	20-29	30-39	40-49
Asia	4	1	2	2	1	0	1	0	0	0
Canada	8	8	1	0	1	3	2	2	0	0
Europe	15	28	2	3	5	1	3	1	1	1
Oceania	8	8	0	0	2	0	4	1	1	0
S. Africa	2	1	0	0	0	2	0	0	0	0
UK	16	7	2	6	5	3	2	0	0	0
USA	61	39	4	11	18	13	9	10	0	0
<b>Total</b>	<b>114*</b>	<b>92</b>	<b>11</b>	<b>22</b>	<b>32</b>	<b>22</b>	<b>21</b>	<b>14</b>	<b>2</b>	<b>1</b>

*\*Living individuals shown by age groups to the right*

## Science and Medicine

Led by Dr. Matt Toth, BSF's Director of Science

### Research Grant Program

At the beginning of 2006, our Scientific and Medical Advisory Board (SMAB), supported by outside experts, evaluated nine proposals requesting funding for scientific research into Barth syndrome in the 2006 grant cycle. Following the SMAB's recommendations and after thorough review, the BSF Board approved and funded seven grants for a total of \$309,200, which are reflected in our 2007 financial statements. These grants have been reported on in our previous newsletter and some of the researchers' results will be discussed at the upcoming Conference in July.

In January of this year, the 2007 grant cycle was completed. Nine highly qualified grant recipients were selected from among the largest number of applications ever received by BSF, and awarded \$330,000 — the largest commitment of funds for research ever awarded by BSF and its affiliates in a single year. The success of this program, now in its sixth year, bears witness to the growing reputation and impact that BSF and its affiliates are creating in the scientific community. This year's award winners and their research studies are reviewed in an article written by Dr. Toth beginning on the front cover of this newsletter. We are excited by the progress that these researchers are making, and the prospects for greater understanding of Barth syndrome improve daily. Equally exciting is that research funded by BSF is having an impact on other disorders (see the article on Diabetes research on page 19) and creating linkages that we hope will lead researchers in other disorders to make discoveries that will provide insights back to Barth syndrome as well!

### Barth Syndrome Registry and DNA Bank

This program has just completed its second year under the leadership of our co-investigators: Dr. Carolyn Spencer, now at Children's Hospital in Boston and Dr. Barry Byrne at the University of Florida. With the help of the Institute of Child Health Policy at the University of Florida and their expertise in building medical databases, we are now entering the second phase of the project — augmenting the self reported data initially gathered from 43 families, with detailed data abstracted from the patients' medical records. This databank, linked to DNA samples from each child now kept in our biorepository, will prove an invaluable resource for researchers and will provide a much needed baseline with which to evaluate any future therapies. Clearly, more data from more affected individuals and their families increases the impact this effort can have on understanding the evolution of Barth syndrome in patients over time and linking the clinical manifestations to possible genetic variations found in the matching DNA samples. Families attending the clinics held prior to the upcoming BSF Conference in

Clearwater, Florida will be able to directly advance the future of scientific research by updating or making their initial contributions to the Barth Syndrome Registry and DNA Bank.

### Scientific and Medical Advisory Board

In July of 2007, Dr. Matt Toth convened a full day meeting of scientists and researchers interested in Barth syndrome to map out the most promising scientific paths to accelerate discoveries that will lead to improved treatments and eventually a cure for Barth syndrome. Also in attendance were six members of the BSF Scientific and Medical Advisory Board. The group identified the highest priorities for accelerating research including the need for a mammalian model (e.g. a mouse or a rat with Barth syndrome), specialized antibodies that will help identify the presence of human tafazzin proteins, and high throughput assays that can be used in areas such as newborn screening. This "roadmap" is already guiding BSF investments including grants and contract research into all three areas identified above.

### Physician Awareness

Led by Steve Kugelmann

During 2007, BSF and its affiliates sent representatives to and/or set up our booth at eight medical conferences attended by pediatric physicians who may well diagnose and treat a Barth patient. Conferences at which BSF had a visible presence included:

- Child Cardiology 2007 (Children's Hospital of Philadelphia), Orlando, FL
- American College of Medical Genetics, Nashville, TN
- Society for Inherited Metabolic Disorders, Nashville TN
- Pediatric Academic Societies, Toronto Canada (BSF Canada)
- United Mitochondrial Disease Foundation, San Diego CA
- Clinical Cardiovascular Genomics, Cold Spring Harbor, NY
- American Heart Association, Orlando FL
- American Society of Hematology, Atlanta GA

Maintaining a presence at these conferences may entail setting up the BSF booth, handing out brochures and answering questions about Barth syndrome and encouraging Barth syndrome researchers to deliver scientific presentations and posters, all designed to increase awareness of Barth syndrome, its symptoms and BSF and its affiliates. Many of our new families are diagnosed or introduced to BSF as a direct result of their physicians learning about Barth syndrome at these meetings. BSF representatives at these conferences included Steve Kugelmann, Jan Kugelmann, Shelley Bowen and Dr. Matt Toth.

*(Continued on page 6)*

## 2007— A Time for Perspective

### Contributions

BSF raised \$674,000 from almost 1,000 individual contributors in 2007. These financial supporters are so vital to the continued health of BSF. Without your contributions, none of the important programs described above would be possible. Your donations fund advances in research. You pay for our volunteers to attend the medical conferences. You fund physician awareness and the cost of operating and maintaining our website and listservs — such vital links for our families and physicians. Our upcoming BSF Conference at the Belleview Biltmore Resort in Clearwater, FL will cost over \$150,000 to run and is a great investment.

Equally critical are the families and friends who led the fund raising efforts that raised this money. People don't give to institutions or charities, they give to a cause they have come to believe in. A rare and obscure disorder like Barth syndrome is not a high profile cause. There are no celebrities endorsing BSF on Oprah, and most people have never heard of it let alone known someone who is affected. Except our donors.

Every one of them knows someone with Barth syndrome personally or has been told the story by a good friend who does. Every donor was asked to donate to BSF by someone. These are our heroes. The ones who ask. The ones who tell their friends and family of the challenge of Barth syndrome and the hope of BSF. The ones who understand that without financial support, progress stops, families are condemned to isolation and hope dies. So our thanks go to our donors and we ask you to please keep BSF at the forefront of your generosity, even in these difficult economic times. But we reserve our highest praise and deepest appreciation for our fund raisers, for they keep the lights shining... literally!

**Scott Oldewage** – Scott's boss, Ed Pace continues to support Scott's colleagues at Lake City Trucks and Lake City International in Utah, who contribute to BSF through their workplace giving program. LCT and LCI match all employee donations and Ed Pace makes a personal donation in each month that his companies are profitable. Ed has met only one person affected by Barth syndrome — Scott and Casie's son Christian — but his monthly generosity reaches families around the globe.



**Randy Buddemeyer** and the C. B. Richard Ellis Annual Charity Golf Tournament, which once again has set a new record for money raised by CBRE for BSF, doubling their previous year's donation. Randy and Leslie are great spokespersons for BSF, and their friends and business colleagues respond to their requests for donations... and have fun playing golf as well! (*Photo 1*)

**Jan and Steve Kugelmann's** annual BSF Drive for a Cure Golf Tournament. This is the granddaddy of BSF Golf Tournaments as it enters its fifth year in 2008. Jan and Steve have a loyal following who show up every year to have fun, watch the local police helicopter do the Chopper Dropper and to raise money for BSF. It's a labor of love for Jan, Steve and friends. (*Photo 2*)



For the seventh straight year the **McCurdys** have sent a simple letter to a growing list of friends from high school, college and graduate schools, work, church and parents of their children's friends from school and around town. The letter makes a simple case, from the McCurdy's hearts asking their friends to once again include BSF in their charitable giving... and every year, their friends respond positively. They say, "We are happy to help in this small way. We know how important this is to you and Will."



**Sue Wilkins** started the Woody Varner Fund for BSF in honor of her Dad and added her Mom's name after she passed away last year. The Paula and Woody Varner Fund has been a major fund raiser for BSF and a wonderful way to create a lasting memorial for two people who were so loved by so many.

**Liz and John Higgins** love to bowl. So do their friends. Out of such simple pleasures came the annual Bowling for Barth fundraiser which is fast becoming an institution in Highland Lakes, NJ. Who says fundraising has to be hard? *(Photo 1)*

**Tom and Laurie Monahan** seem to find an endless number of ways to raise money for BSF, usually involving the Brockton Rox, sports and the Charlie Horse Sports Bar! No matter what the event, Tom's tireless promotion and great sense of humor and Laurie's organizational skills insure that every event is memorable... and a fundraising success.



Barth syndrome does not run in **Gary Rodbell's** family, but Gary doesn't ever seem to stop running for BSF. Running, swimming and biking that is. He is gathering a growing herd of triathletes who train with him and raise money for BSF. In 2007 he and fourteen other athletes raised money for BSF by competing in the Westchester Triathlon in NY. In 2008 some of these iron-people are running in a half Ironman in Laconia, New Hampshire in August and many more are entered again in Westchester, NY on September 21. Coach Gary and "Team Will" guarantee another "win" for Barth! *(Photo 2)*



When **Amer and Jay Randall's** triplets had their fourth birthday, the Randalls celebrated the occasion with a party and invited all of their friends to add to the festivities with a gift for the Barth Syndrome Foundation. Since two of the triplets are affected by Barth syndrome, and all of their friends had been asking what they could do to help, this was a natural and welcome way to mark the day. *(Photo 3)*

Over the last year, in addition to the Paula and Woody Varner fund, Memorials were established by the families of **Tony Satula** a friend of the McCurdys in Larchmont, NY and **Rob Lochner**, Lynda Sedefian's brother in upstate New York. I hope that we can all be as strong and as generous as these families, to think of others despite the loss and sadness they are experiencing. We are eternally grateful.

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# Research Grants Showcase Increased Barth Syndrome Awareness and Interest

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dysfunction causes changes using cellular models in yeast, in cardiac cells, and in white blood cells. Two projects are investigating if there are BTHS patients that have been overlooked, another seeks to make a rat model of BTHS, while another looks into how cardiolipin works on the molecular level.

The following is a summary of the main focus of each individual grant with some thoughts of what value it will bring towards achieving our ultimate goal. The number and breadth of these awards clearly demonstrates the real progress and the increased exposure of BTHS research to the scientific and medical community.

In addition this year's cycle has greatly benefited from the increased funding provided by the Barth Syndrome Foundation of Canada and by the Barth Syndrome Trust (UK and Europe). Our worldwide family of organizations continues to grow and mature into something we can all be proud of.



**Miriam Greenberg, PhD, Professor and Associate Dean, Wayne State University, Detroit, MI**

***"Perturbation of the osmotic stress response in cardiolipin-deficient mutants"***

Prof. Greenberg uses brewer's yeast as a model system to uncover the biochemical connections between the lipid cardiolipin and the genes that affect cardiolipin such as tafazzin—the gene which, when mutated in humans, causes BTHS. Using certain yeast mutants that are deficient in cardiolipin and which have a shortened lifespan, Prof. Greenberg has discovered other mutated genes that are able to restore this lifespan. After testing heat stress, osmotic stress, and screening 80 stress pathway mutants, only mutations in the HOG1 pathway were able to suppress this lifespan shortening of the original cardiolipin-deficient mutants.

HOG1 is a gene found by other investigators and is involved in a cell's response to stress like the lack of water. HOG1 stands for high-osmolarity glycerol. Because cardiolipin is dysfunctional in BTHS patients, this discovery shows that we may be able to find other pathways and other genes that can ameliorate some of the problems associated with cardiolipin deficiency. How is HOG1 relevant to BTHS? The HOG1 pathway is equivalent to the P38 MAP Kinase in human cells, and we know that P38 MAP Kinase is involved with cardiomyopathy, a defining characteristic of BTHS. These observations point to a parallel equivalence between yeast and humans which is not evident at first impression. Prof. Greenberg seeks to extend and build on these observations by examining the expression and

phosphorylation of the HOG1 gene product and its protein targets. Using this information (e.g. inhibition of the P38 MAP Kinase), testable hypotheses for finding treatments for BTHS can be envisioned.



**Carol P. Moreno-Quinn, MD, PhD, Assistant Professor, Medical College of Wisconsin, Milwaukee, WI**

***"Creation of a rat model of Barth syndrome"***

The 2006 Nobel Prize in Medicine was awarded to Mello and Fire for their discovery of "RNA interference." Using techniques that exploit this Nobel Prize-winning idea, Dr. Moreno-Quinn will make a strain of rat that is deficient in tafazzin expression. Specifically, Dr. Moreno-Quinn will add a transgene to the rat genome that lowers tafazzin expression using RNA interference—a "knockdown" of the tafazzin gene. This relatively new technology is expected to recapitulate the defects that patients with BTHS endure. Dr. Moreno-Quinn will then analyze these knockdown rats to determine if their physiology resembles that experienced by BTHS patients. A mammalian model of BTHS will be a powerful tool in advancing BTHS research, and it has been a goal of many researchers over the years.



**Quan He, PhD, Research Scientist, Henry Ford Hospital, Detroit, MI**

***"Are reactive oxygen species involved in the development of dilated cardiomyopathy in Barth syndrome?"***

Using the same Nobel Prize-winning idea of Mello and Fire, Dr. He will lower tafazzin expression in rat neonatal cardiac cells by siRNA oligonucleotides and monitor the effects. Dr. He believes that tafazzin dysfunction causes cardiolipin loss which generates reactive oxygen species (ROS). These ROS cause changes in cardiac cells which eventually lead to apoptosis and dilated cardiomyopathy—a critical problem in BTHS patients. If these experiments are successful then this cardiac-cell model of BTHS will be very valuable for BTHS research and for heart failure research in general.



**Matthew R. G. Taylor, MD, PhD, Associate Professor and Director of Adult Clinical Genetics, University of Colorado Health Sciences Center, Denver, CO**

***"Prevalence of Barth syndrome in adult cardiomyopathies"***

By using mRNA hybridization methods, Prof. Taylor will quickly screen for coding changes in tafazzin mRNA in over 200

samples from his Center's collection of adult cardiomyopathy patients. If there are positive hits in this registry, DNA sequencing of the tafazzin gene will be used to identify the mutation. If Prof. Taylor finds adults with tafazzin mutations, then conventional ideas about the incidence frequency for BTHS will have to be re-examined. Because BTHS is a very rare genetic disease, reliable frequencies for its incidence are difficult to obtain. There are only a few cases of men with BTHS that are in their 30's and 40's. Finding more of these patients will increase our understanding of BTHS and may lead to clues about how to effectively deal with the condition.



**David Dale, MD, Professor of Medicine, University of Washington, Seattle, WA**  
***"Neutropenia in Barth syndrome"***

Building on previous BSF-funded research, Prof. Dale will use the promyelocytic cell line HL60 to establish a cellular model of neutropenia caused by BTHS. Using a shRNA vector that transiently decreased tafazzin mRNA expression, Prof. Dale will now make a permanent cell line that can be better analyzed for the traits expected in neutropenia. This cell line model of BTHS will approximate the conditions seen in BTHS neutrophils and will be a vehicle to test hypotheses designed to ameliorate this type of neutropenia.



**Taco Kuijpers, MD, PhD, Professor, University of Amsterdam, Amsterdam, The Netherlands**  
***"Neutropenia in Barth syndrome: new in vitro models to study BTHS neutrophils"***

Using compounds that poison or disable mitochondria function, Prof. Kuijpers will expose the promyelocytic cell line HL60 and will then monitor various parameters that simulate the conditions observed in neutrophils from BTHS patients. Prof. Kuijpers's hypothesis implicates a defect in electrical potential across the mitochondrial membrane—an observation for which he has provided evidence. It is hoped that these experiments will bring about a more mechanistic understanding of how neutropenia occurs in BTHS.



**Richard Epand, PhD, Professor, McMaster University, Hamilton, ON, Canada**  
***"Consequences of the alteration of cardiolipin structure on the properties of the mitochondrial membranes"***

With the help of a synthetic chemist, Prof. Epand will examine the titration or hydrogen donor behavior of various cardiolipin species, both symmetric and asymmetric. This biophysical behavior will be analyzed in different

membrane curvature environments and in the presence of certain proteins. By understanding what biophysical differences are occurring in membranes with different amounts and different types of cardiolipin, Prof. Epand should be able to show a mechanism by which cardiolipin dysfunction may cause many of the BTHS symptoms.



**Susan Kirwin, Senior Research Associate, Assistant Director, Nemours Children's Clinic, A. I. duPont Hospital, Wilmington, DE**  
***"Barth syndrome testing: Are we missing some patients?"***

By using tafazzin mRNA analysis from blood samples of BTHS and non-BTHS patients, Ms Kirwin will determine if mRNA differences can be used as a diagnostic factor for BTHS. Using data obtained from a clinically diagnosed BTHS patient, Ms Kirwin has shown evidence for an mRNA dysfunction but without a coding mutation in the tafazzin gene. This result means that the spectrum of mutations at the tafazzin gene that gives rise to BTHS has to be expanded to include these types of non-coding mutations. These mRNA results may lead us to derive a correlation between tafazzin mRNA quality and the severity of the symptoms of BTHS patients. A better understanding of what is a normal and what is an abnormal mRNA pattern for tafazzin expression will lead to the identification of patients who have been misdiagnosed in the past, and it may tell us more about tafazzin mRNA expression and BTHS symptoms.



**Christopher R. McMaster, PhD, Professor, Dalhousie University, Halifax, Nova Scotia, Canada**  
***"Synthetic genetics towards understanding Barth syndrome cell biology"***

Dr. McMaster will use a robotic screening platform to systematically cross the tafazzin deletion strain of yeast with 5,000 other yeast mutants to determine if any of these 5,000 genes interact with tafazzin. By using systematic genetics to identify which genes interact with tafazzin, he will attempt to uncover potential modifiers of tafazzin dysfunction which could lead to new ideas about a treatment for BTHS.



# Family Sessions of the 4<sup>th</sup> International Scientific, Medical and Family Conference

(Continued from page 1)

personal experiences. In the end, you will have more strategies to help you cope with the everyday situations that are so difficult to articulate to others.

As parents, we are called upon to look for mentors, partners in care, and 'big picture' thinkers who are willing to take the time to learn about this complex disease that may only affect one child in their busy practice. We have had to learn, very quickly, how to convey information about our child's health, and the disease itself, in such a way that we are taken seriously and, frankly, in a way that we know that our message has been heard and carefully considered.

***“The Barth syndrome conference is exhausting and exhilarating all at the same time.***

***I don't want to waste a moment sleeping because I want to absorb every possible moment. I want to learn all that I can.”***

There are unique challenges in managing the care of someone with Barth syndrome. At times it seems as if there is so much to learn, and it is simply overwhelming. Yet, never has there been anything more important than to learn about Barth syndrome when a life depends on it.

## CONFERENCE OVERVIEW

### Welcome Reception (Monday Evening, July 21, 2008)

An informal gathering for Barth families! Meet new families, reunite with old friends, and have fun!

### Barth Clinics (July 22–23, 2008)

#### Families Sharing Invaluable Information

Two days of Barth clinics where both families and clinicians share and learn valuable information about the clinical aspects of Barth syndrome. This exchange between families and clinicians about the many nuances of Barth syndrome gives rise to opportunities to explore new ideas and discuss issues of common theme. Data collected as a result of these clinics will feed the Barth Registry to further the understanding of this disorder.

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

#### Looking To the Future!

The Family sessions will run simultaneously with the Scientific and Medical sessions. At the Family sessions, medical specialists will participate in a series of interactive panel discussions on a variety of aspects of Barth syndrome. Topics covered will range from scientific insights into the underlying genetic, biochemical and metabolic causes of this disorder to clinical manifestations of Barth syndrome and the latest on how these can best be treated. Topics at Family sessions will include, but will not be limited to: cardiac concerns, potential arrhythmia, neutropenia and infection, unusual growth patterns, nutrition and eating problems, pain, fatigue and exercise intolerance—including therapies and devices to improve stamina.

***“During this event I am surrounded by people who have traveled a similar journey that I am going through. I am among people who simply ‘get it,’ and that is rare. My son isn't different here. His brothers and sisters are with other children who are equally as thoughtful as they are and, on this occasion, life-time friendships and new partners in this journey are forged.”***

**MOST IMPORTANTLY**, there is nothing more affirming for a parent or an affected individual than to know that just down the hall from the Family sessions are experts in Science and Medicine from around the world who have gathered in one location to focus on the many aspects of Barth syndrome. There is no greater opportunity for those involved in the study of Barth syndrome to learn from others. It is only through the collaboration and communication of successes and failures in scientific research that knowledge is gained and new research is stimulated. It is at this Conference where invaluable information will be exchanged which will not only improve outcomes in science, but will likely improve the outcome for those with Barth syndrome.

There is a comfort in knowing that history is in the making and that we, as families, are a part of this process!

### Friday Night Social Event (Friday Evening, July 25, 2008)

An evening of fun and socialization for ALL Conference participants! This casual social event brings together our families, clinicians, physicians, scientists, volunteers and those who have an interest in Barth syndrome.

(Continued on page 36)

# Scientific and Medical Sessions of the 2008 Barth Syndrome Conference Will Build on Previous Success

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

“ It is rare to convene a meeting like our Barth syndrome conferences where one can hear presentations focusing on the molecular level, continuing with animal models of disease, and extending into clinical presentations. ... The interactions among all of the Conference participants, the shared experiences, and the new ideas that are discussed will alter the course of Barth syndrome research and treatment. ”

**T**he Scientific and Medical portion of the Barth Syndrome Foundation's 2008 4<sup>th</sup> International Scientific, Medical and Family Conference promises to be an exciting and informative meeting, just like previous years. More than 23 speakers are scheduled to speak over two days (July 24—25) on various topics related to the research about, and the treatment of, Barth syndrome. In addition, like the 2006 Conference, there will be a poster session which will be presented during the late afternoon of Thursday, July 24<sup>th</sup>. Over 14 posters will be presented by the primary authors who will be available to speak one-on-one with the Conference attendees. This year the posters will be available for inspection during the entire Conference so that everyone may have a chance to view them.

As in past years, the Scientific and Medical sessions will be held concurrently with the Family sessions of the Conference. Lunch and the presentation of the first *Paula & Woody Varner Pioneer in Science and Medicine Award* will be held at 12 noon on Thursday, July 24<sup>th</sup>. Participants from both sessions are invited to attend. In addition, the evening of Friday, July 25<sup>th</sup> is scheduled as a social event for ALL Conference attendees where physicians, scientists, families and volunteers can relax and enjoy themselves.

Our unique Conference, which also includes two days of clinics (July 22—23) to gather valuable data about Barth syndrome, has become a special event for the Barth Syndrome Foundation (BSF) community. This meeting is important in bringing together many of those touched by this rare condition. It serves to educate members, to renew old friendships, and to connect with other Barth individuals, their families, and the clinicians and scientists who are dedicated to finding improved ways to treat this disease. The opportunity for personal interactions with the very people who are affected by Barth syndrome invigorates those who are charged to find a way to treat it. It is a powerful inducement to keep focused on one's research and clinical goals.

Many speakers will be presenting information directly related to the research grants they have received from the BSF and from the affiliates of the BSF. Because of the central importance of the tafazzin gene, there will be several talks about understanding tafazzin's functional

role in causing Barth syndrome. New ideas about how tafazzin gene expression is dysfunctional in various Barth syndrome individuals will also be presented. Results from cellular and animal model systems with altered tafazzin expression will add new layers to our basic understanding. The discussions that follow these talks should cover many topics from the very basic ideas of the biophysical mechanisms of cardiolipin in the mitochondrial membrane, through which genes interact with tafazzin, and eventually to how all of this information may help design or test new treatments for Barth syndrome.

Presentations of a clinical nature will be very informative to physicians who care for those who have Barth syndrome. Because affected individuals are few and far between, the common problems they face are often unknown to them and to their treating physicians. Many physicians find it useful to meet with other Barth syndrome patients and attend portions of the clinics early in the week. By meeting with other treating physicians, asking questions, and pooling the clinical experiences of the medical community, this Conference will benefit attending physicians so they can provide the best care and treatment. The Conference allows both doctors and patients to observe and to ask questions about how others are dealing with this disease and what issues may be serious enough to warrant close monitoring.

It is rare to convene a meeting like our Barth syndrome conference where one can hear presentations focusing on the molecular level, continuing with animal models of disease, and extending into clinical presentations. It is even rarer to have those individuals most affected by a disease become an integral part of the same conference. Nevertheless, the interactions among all of the Conference participants, the shared experiences, and the new ideas that are discussed will alter the course of Barth syndrome research and treatment. This is the goal of every BSF conference, and through the generosity, hard work, and imagination of so many people, we will achieve it once again.



# Moving Ahead: Uniting Families and Researchers

## Barth Syndrome Registry and DNA Bank Enters the Second Phase

By Melissa K. Maisenbacher, MS, CGC; Genetic Counselor, University of Florida Departments of Pediatric Genetics and the Congenital Heart Center, Gainesville, FL, USA

Over the past two years, The Barth Syndrome Foundation and the University of Florida have built the Barth Syndrome Registry and DNA Bank specifically for individuals with Barth syndrome (BTHS). The goal is to collect DNA samples and data on individuals with Barth syndrome from across the world to enable medical professionals and researchers to learn more about the natural history, medical complications, and underlying biochemical and molecular basis of Barth syndrome—and to do all these things faster.

The first phase of data collection was the “self-reported” data (e.g. demographics, family history, basic medical and developmental history, etc.). Initially, 43 families joined the Registry, including families from Australia, Canada, the United Kingdom, and the United States. Although termed the “first” phase, self-reported data will be collected continuously, with periodic updates of the database for all enrolled patients. These updates will allow for researchers to follow the disease progression and provide the ability for longitudinal studies (studies that follow patients at regular intervals over an extended period of time).

Queries to the database of self-reported data have mainly been descriptive in nature. Recent queries included, looking at the age of presentation of cardiomyopathy (Figure 1), and noting the specialist/individual who made the initial diagnosis of Barth syndrome in each patient (Figure 2).

The second phase of data entry encompasses building a separate medical database, collecting records, and abstracting data from enrolled patients’ medical records. The database will also include medical or laboratory test results and specific hospitalization records. The medical database is in the initial design stages utilizing the expertise of medical professionals at the University of Florida, Boston Children’s Hospital and the Institute for Child Health Policy at the University of Florida.

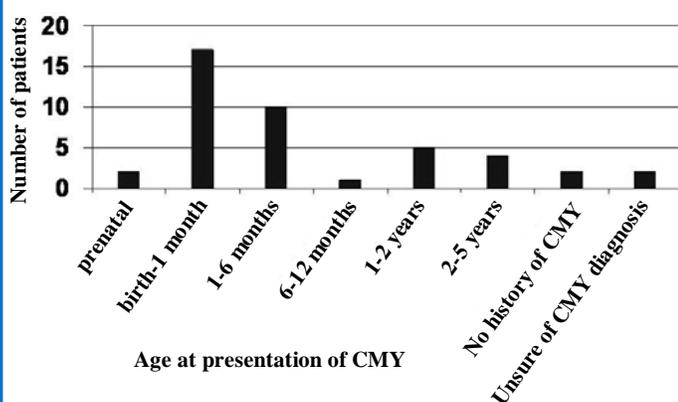
By collecting both types of information, self-reported data and data abstracted from medical records, a comprehensive and high quality database has been created.

This second phase of the Barth Syndrome Registry and DNA Bank is envisioned to become a rich resource not only for BTHS researchers, but for other researchers who are studying the larger picture of cardiomyopathy, myopathy, or neutropenia. It may be possible that a better understanding of how BTHS produces various symptoms, may positively impact our grasp of other related human diseases.

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).

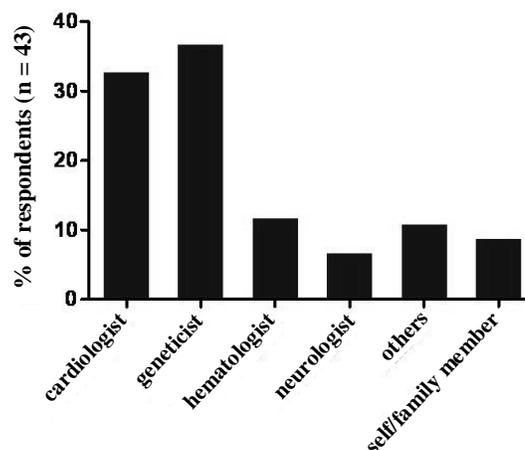


**Figure 1:** Age at diagnosis of cardiomyopathy (CMY) in boys with Barth syndrome (43 patients)



Barth Syndrome Registry and DNA Bank  
University of Florida; [barthregistry@peds.ufl.edu](mailto:barthregistry@peds.ufl.edu)  
<http://www.peds.ufl.edu/barthsyndromeregistry>

**Figure 2:** First to arrive at the diagnosis of Barth syndrome



Barth Syndrome Registry and DNA Bank  
University of Florida; [barthregistry@peds.ufl.edu](mailto:barthregistry@peds.ufl.edu)  
<http://www.peds.ufl.edu/barthsyndromeregistry>

# ANNOUNCEMENT

## 2008 Request for Research Proposals

The Barth Syndrome Foundation, Inc. (BSF) is pleased to announce the availability of funding for research on the natural history, biochemical basis, and treatment of Barth syndrome.

### Background

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

### Types of Proposals Sought

We are most interested in providing "seed money" to be used by experienced investigators for the testing of initial hypotheses and collection of preliminary data leading to successful long-term funding by the National Institutes of Health (NIH) and other major granting institutions. In addition, we are especially interested in attracting new investigators to the very interesting field of Barth syndrome research.

### Funding

We anticipate awarding several one- or two-year grants of up to \$40,000 each. Funds will be available as soon as the successful grant applicants have been notified.

### Process

We have a simple grant process. Applications should be of 10-15 pages in length and must follow the instructions listed on the BSF website ([www.barthsyndrome.org](http://www.barthsyndrome.org)). In general terms, detailed information about the specific aims, significance, research design and methods, personnel, and budget will be required, along with evidence of application to the relevant Institutional Review Board for any work involving human subjects.

Completed proposals will be forwarded to the BSF Scientific and Medical Advisory Board (as well as outside reviewers, in certain cases) for evaluation. Based on the recommendations of the Scientific and Medical Advisory Board, the BSF Board of Directors will make the final funding decisions for the grant applications.

### Deadline

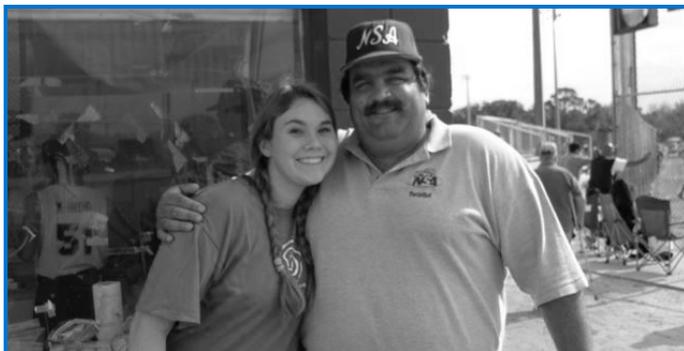
The deadline for submission of completed research grant applications from interested researchers is October 31, 2008. Grants will be awarded early March 2009.

### Contact Information

Matthew J. Toth, PhD  
Science Director  
Barth Syndrome Foundation, Inc.  
[mtoth@barthsyndrome.org](mailto:mtoth@barthsyndrome.org)

# Softball with a Heart—A “Sweetheart Ball” Fundraiser

By Chelsea Kugelmann, Extended Family Member, Florida, USA



*Chelsea, with the support of National Softball Association’s Florida state director, John Wisniewski, hosted a ‘Sweetheart Ball Fundraiser’ to raise funds for BSF.*

I was almost five years old when my cousin RJ was born; far too young to comprehend the flurry of activity and obvious concern from my family that immediately followed. He was moved to a children’s hospital almost immediately because of his serious heart problems, and was placed on a heart transplant list. It was some time before he was diagnosed, but fortunately one of the experts identified his symptoms as those of Barth syndrome. Over time, his condition stabilized, he was removed from the transplant list, and he has been able to lead a relatively normal life. I have always known that he has a rare disease, and that limitations have to be placed on his activities and exposure to germs, but never understood the complex details of his condition until last year through my studies at school.

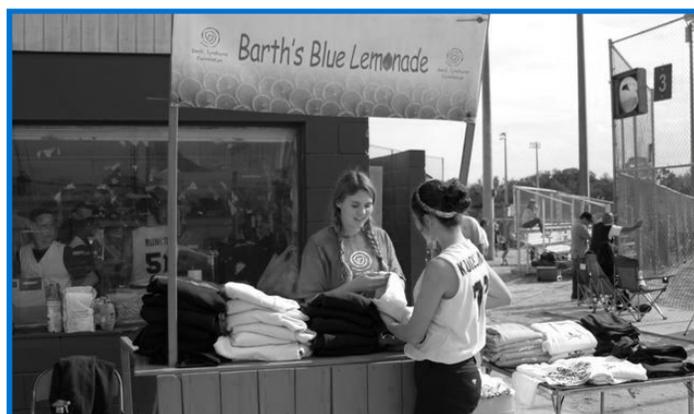
I am enrolled in the International Baccalaureate’s Middle Years Program (MYP) at Cocoa Beach Jr/Sr High School in Cocoa Beach, Florida. This is an extremely challenging scholastic program, which has overall goals to not only develop a student intellectually, but also in a way that makes them responsible members of the community. In the last year of the MYP program (10<sup>th</sup> grade), each student is required to complete a personal project. This project is intended to be something that is important to the student, aids their personal development, and reflects the positive lessons that have been taught throughout the program.

The idea for a personal project came last year as I was working on a Biology assignment. We were to select a genetic disorder and develop a detailed report, which was to include the genetic disposition of the disorder, the DNA thread that holds the malfunction, and to elaborate on the disease before a class of freshmen Biology Honors students. I immediately thought of Barth syndrome and began researching the topic. The Barth Syndrome Foundation website was an absolutely fabulous tool,

providing all the technical information needed. Volunteering at our local hospital was an opportunity to get expert information from one of the local doctors who had treated RJ when he was born. I learned so much about this devastating disorder. What touched me most was the intense need for research and the fact that a large percentage of the funds for that research basically had to be raised by the families and friends of those affected. I became inspired to do something to help out.

I decided to host a softball tournament to raise money for Barth syndrome. Once setting the idea in stone, I began researching what would be needed in order to make this tournament a success. The first big accomplishment was gaining the assistance of the National Softball Association’s (NSA) Florida State Director, John Wisniewski. He loved the idea, and said he would help pull together the “Sweetheart Ball” tournament, to be held in February 2008. Having the NSA host the tournament saved a lot of work. They took care of securing the site location, registration of the teams, insurance, officiating, and awards, leaving me to focus on advertisement and fundraising.

The primary fundraising was through concession, sales of handmade sparkly headbands for players, and a 50/50 drawing. Volunteers helped out in the concession stand and through sales of the headbands and raffle tickets. After a long weekend of very hard work, we counted up the profit. We had made just over \$1,000! It was such a wonderful experience. I learned what it takes to organize and plan an event such as this, as well as how to deal with some of the problems and roadblocks that inevitably come your way. But most importantly, I learned the extraordinary feeling that comes from making a difference and truly helping a great cause. I will remember this experience for the rest of my life, and hope to be able to continue in the future with similar events.



# Barth Syndrome Trust Volunteers Share Work and Ideas

By Charlotte Sharpe, Mum of Affected Child, South West England

I attended a BST volunteer workshop for the first time on 12 April 2008. It was great to see everyone and as soon as I arrived (late!) I got started sticking labels onto envelopes for mailing to doctors. That was the easy stuff!

I chatted away to some of the other parents and as usual we swapped stories about our boys, how similar they are, and yet how very different too. My son is nearly five and was diagnosed at about a month old, so I've always felt like a relatively new Barth mum. However, there were newer ones than me and I was able to appreciate how diverse our stories were. Many of us come from quite different backgrounds, but are united by a common experience.

There were a number of people, mums and dads, a young man with Barth syndrome, affected family members and friends who were there to give of their time, support and IT skills!

After lunch we split into two groups; one to pursue fundraising ideas and the other to "brainstorm" ideas for a leaflet to be sent to parents of newly diagnosed children. This was harder than any of us imagined. Of course we all had our opinions about what should go into the leaflet, but our different experiences of Barth were highlighted by the dilemmas that absorbed us. Some wanted as much information as possible, others as little as possible. Trying to pick the right tone for the wording, let alone deciding what information to include had us all scurrying to recall the emotions we felt when we received our children's diagnosis.



Awareness mailing is thirsty work. Greg Manton makes the tea!

It's easy as a mum whose child was diagnosed within the last few years to forget that many have been there before. Mums of affected boys have been toiling over publications like these for many years now and we are all only as well informed as we are, thanks to those pioneer mums who have sought us out and brought us all together.

I'm not sure how much was achieved towards writing that leaflet. Possibly we asked more questions than we answered, but it will only be by continuing these efforts that we can carry on offering support and help to the growing numbers of families who are affected by Barth syndrome. ©

## Canadian BSF Volunteers Remain Vigilant and Vibrant!

By Lois Galbraith, Extended Family Member and Volunteer

Our fabulous volunteers rallied again for a workshop experience. Part of the morning was led by a volunteer, volunteers brought us new volunteers, and it was held in the home of yet another volunteer! We are so pleased with and proud of our volunteers. They listen, they learn, they express their thoughts and ideas, they discuss and then they say, "Let me see what I can do about that item," or "I can go on the Internet and see what I can find," or "I will do that again."

Our volunteers factor into every program of the BSF Ca. They fundraise with their own events and hunt down prizes for our golf tournament. They raise awareness by publishing a newsletter and by speaking to their friends about Barth syndrome. Volunteers have edited printed materials, searched websites, knitted, woodworked and baked. They are also involved in the preparation for the upcoming Scientific, Medical and Family Conference. A number of our volunteers will be helping with registration, clinics and other parts of the Conference. We are looking forward to seeing everyone there.



(L-R) Maureen Pitkethly, Celia McGuinness, Carole Clark, Audrey Hintze, Les Morris, Marjorie Bridger, Lynn Elwood, Janet Warren, Lois Galbraith, Wayne Bridger

We continue to learn a great deal from these vivacious volunteers and we are impressed by the willingness, abilities and talents of our group. Volunteers are exciting and welcomed partners to our organization. We applaud all that they do for us! ©

## 2007— A Time for Perspective

(Continued from page 7)

### Financial Condition

BSF's financial condition remains very strong. Our programs and their cost continue to grow, but we were able to raise enough money to cover these costs and still produce a small surplus in 2007. Our investments produced enough income to cover our administrative and fundraising costs. If we want to continue to grow and have a larger impact on the lives of our children we will have to find additional sources of revenue in the future, but for now we can look forward to meeting these challenges with confidence.

<b>The Barth Syndrome Foundation, Inc.</b>		
<b>Statement of Activities</b>		
<b>For the Years Ended December 31</b>		
	<u>2007</u>	<u>2006</u>
<b>Public Support and Revenue</b>		
Contributions	\$ 674,457	\$ 1,018,888
Other	\$ 116,505	\$ 66,816
<b>Total Support and Revenue</b>	<b>\$ 790,962</b>	<b>\$ 1,085,704</b>
<b>Expenses</b>		
Program Services	\$ 596,095	\$ 550,838
Management and General	\$ 81,864	\$ 98,875
Fund Raising	\$ 12,372	\$ 4,115
<b>Total Expenses</b>	<b>\$ 690,331</b>	<b>\$ 653,828</b>
<b>Change in Net Assets</b>	<b>\$ 100,631</b>	<b>\$ 431,876</b>
<b>Net Assets - Beginning of Period</b>	<b>\$ 2,329,154</b>	<b>\$ 1,897,278</b>
<b>Net Assets - End of Period</b>	<b>\$ 2,429,785</b>	<b>\$ 2,329,154</b>

<b>The Barth Syndrome Foundation, Inc.</b>		
<b>Statement of Financial Position</b>		
<b>At December 31</b>		
	<u>2007</u>	<u>2006</u>
<b>Assets</b>		
Current Assets	\$ 2,613,769	\$ 2,460,331
Other Assets	\$ -	\$ -
<b>Total Assets</b>	<b>\$ 2,613,769</b>	<b>\$ 2,460,331</b>
<b>Liabilities</b>		
	\$ 183,984	\$ 131,177
<b>Net Assets</b>		
Unrestricted	\$ 1,993,659	\$ 1,939,939
Temporarily Restricted	\$ 436,126	\$ 389,215
<b>Total Net Assets</b>	<b>\$ 2,429,785</b>	<b>\$ 2,329,154</b>
<b>Total Liabilities and Net Assets</b>	<b>\$ 2,613,769</b>	<b>\$ 2,460,331</b>

2007 was another strong year for your Foundation and the first months of 2008 give every indication of continuing that trend. We continue to make solid progress on every program and remain financially sound. We are in the midst of our search for our first Executive Director and the candidate pool looks strong. We hope to be able to introduce you to him or her at the upcoming BSF Conference.

We mourn the loss of one of our own and pray for those of our small community who are facing serious medical challenges. But we also know that as a community we stand united in support for one another no matter how many miles might separate us. Each of us is a shining example of all the good that can come from a small group of people, intensely and unyieldingly focused on a single vision. Thank you for standing with us.

## Randy Buddemeyer Joins BSF's Board of Directors

By Stephen McCurdy, Chairman, Barth Syndrome Foundation, Inc.



**T**he Barth Syndrome Foundation (BSF) is pleased to announce the election of Randy Buddemeyer to the BSF Board of Directors.

As many of you know, Randy is the father of a young man affected by Barth syndrome. He and his wife Leslie have joined the leadership of BSF in off-site planning and development meetings, and they have been active in fundraising and on committees for BSF for many years.

Randy is a Managing Director of C. B. Richard Ellis, one of the largest real estate service companies in the world. His success at CBRE is a testament to the depth of his business experience, judgment, leadership and drive. Randy was identified as having the kind of experience that would benefit BSF and has expressed his gratitude for the invitation and opportunity to help lead BSF on its mission.

Randy was elected unanimously by the Board at the close of 2007 for a three-year term. He is the third Board Member to be added to the BSF Board in the last two years. The Board believes strongly that we must continue to diversify our membership, seek out new resources and experience to lead BSF, and continuously enrich our volunteer and leadership base so that BSF will remain a strong, vital and growing organization until our mission is complete.



## Open Position: Barth Syndrome Foundation Executive Director

By Joseph McCormack, McCormack & Associates

Several months ago, the Barth Syndrome Foundation began a search for the organization's first Executive Director. We are being assisted by McCormack & Associates, a retained executive search firm that specializes in senior level searches for nonprofit organizations nationally. We are now well along in this process and are pleased to report that several highly qualified candidates are emerging and being vetted by the Board's search committee consisting of Shelley Bowen, Steve McCurdy and Susan Osnos. The selection process includes full reference and background checks, and multiple meetings with the search committee, the BSF Board and consultations with the Presidents of our international affiliates and BSF's staff — Matt Toth and Lynda Sedefian.

We are searching for an individual with experience in non-profit management at the executive level, demonstrated ability in strategic planning, development, communications and volunteer management. Experience in a field related to medicine and/or rare disorders and patient advocacy would be a plus, as would the ability to thrive in a virtual environment. The Board of Directors expects that the successful candidate will work in close collaboration with BSF's President Shelley Bowen, who will continue to report to the Board and to serve as the liaison to the families affected by Barth syndrome. Shelley will also retain responsibility for physician awareness programs and serve as the primary spokesperson for the organization. The new position will report to the Board, will bring added executive level expertise to an already thriving leadership team and will support and encourage this team to take the foundation to new heights of success. We hope to have the new Executive Director on board in time to be introduced at BSF's International Conference in July.

For more detailed information on the position, please visit the Barth website or the website for McCormack & Associates at [www.mccormackassociates.com](http://www.mccormackassociates.com) and click on Current Searches.

We will continue the search until we have a signed agreement with the best candidate, so if you have a prospect or candidate to suggest, please contact our search firm directly at:

**Joseph A. McCormack or Kevin Chase**  
**McCormack & Associates**  
10061 Riverside Drive, #890  
Toluca Lake, CA 91602  
search@mccormackassociates.com  
**(323) 549-9200 TEL (323) 549-9222 FAX**

## What is Barth syndrome?

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

The cardinal characteristics of this multifaceted disorder may include the following in various combinations and degrees, even within the same family:

**Cardiomyopathy:** Heart muscle weakness. This, combined with a weakened ability of the white blood cells to fight infections, represents the greatest threat to those individuals with BTHS. There also can be a risk of serious arrhythmias.

**Neutropenia:** Reduction in the number of "neutrophils," a type of white blood cell that is extremely important in fighting bacterial infections. The neutropenia may or may not follow a regular cycle, but either way, it puts Barth individuals at increased risk of serious infections.

**Muscle Weakness and General Fatigue:** All muscles in a Barth individual, including the heart, have a cellular deficiency which limits their ability to produce energy, causing extreme fatigue during activities requiring strength or stamina—from walking, to writing, to growing.

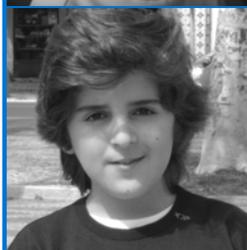
**Growth Delay:** Abnormal growth pattern, similar to, but more severe than, constitutional growth delay. Most boys with Barth syndrome are below average in weight and height, often substantially so, until late teenage years when they usually experience accelerated growth.

**Exercise intolerance:** Extreme fatigue upon physical exertion, beyond that expected from the heart or muscle problems alone.

**Cardiolipin abnormalities:** Cardiolipin (CL) is a critical phospholipid which is not remodeled properly in BTHS. Quantitative and qualitative CL differences have been found in BTHS individuals' tissues and blood.

**Early and accurate diagnosis is key to survival for Barth syndrome boys.**

Historically, boys died of heart failure or infection by three years of age, but today, with improved diagnosis, treatment, and management, the survival rate and future of these individuals are much brighter.



## Recently published articles relevant to Barth syndrome

Listed below are the most recent peer-reviewed journal articles relevant to Barth syndrome that have been added to our extensive library of literature.

Cheng H, Mancuso DJ, Jiang X, Guan S, Yang J, Yang K, Sun G, Gross RW, Han X. **Shotgun Lipidomics Reveals the Temporally Dependent, Highly Diversified Cardiolipin Profile in the Mammalian Brain: Temporally Coordinated Postnatal Diversification of Cardiolipin Molecular Species with Neuronal Remodeling.** *Biochemistry*. 2008 May 3. [Epub ahead of print].

Chen S, He Q, Greenberg ML. **Loss of tafazzin in yeast leads to increased oxidative stress during respiratory growth.** *Mol Microbiol*. 2008 May;68(4):1061-72.

Houtkooper RH, Vaz FM. **Cardiolipin, the heart of mitochondrial metabolism.** *Cell Mol Life Sci*. 2008 Apr 21 [Epub ahead of print].

Finsterer J, Stollberger C, Blazek G. **Prevalence of Barth syndrome in adult left ventricular hypertrabeculation / noncompaction.** *Scand Cardiovasc J*. 2008 Apr;42(2):157-60.

Danos M, Taylor WA, Hatch GM. **Mitochondrial monolysocardiolipin acyltransferase is elevated in the surviving population of H9c2 cardiac myoblast cells exposed to 2-deoxyglucose-induced apoptosis.** *Biochem Cell Biol*. 2008 Feb;86(1):11-20.

Finsterer J, Stöllberger C. **Atrial fibrillation/flutter in myopathies.** *Int J Cardiol*. 2008 Mar 14; [Epub ahead of print].

Finsterer J, Stöllberger C. **Primary myopathies and the heart.** *Scand Cardiovasc J*. 2008 Feb;42(1):9-24.

Schlame M. **Cardiolipin synthesis for the assembly of bacterial and mitochondrial membranes.** *J Lipid Res*. 2007 Dec 12; [Epub ahead of print].

Garrett TA, Kordestani R, Raetz CR. **Quantification of cardiolipin by liquid chromatography electrospray ionization mass spectrometry.** *Methods Enzymol*. 2007;433:213-30.

Leonard JV, Morris AA. **Diagnosis and early management of inborn errors of metabolism presenting around the time of birth.** *Acta Paediatr*. 2006 Jan;95(1):6-14.

# New Research Highlights Common Mitochondrial Dysfunctions in both Diabetes and Barth Syndrome

By Xianlin Han, PhD, Division of Bioorganic Chemistry and Molecular Pharmacology, Washington University School of Medicine, St. Louis, Missouri, USA

**C**ardiolipin (1,3-diphosphatidyl-*sn*-glycerol) is a class of mitochondrial-specific glycerophospholipids in eukaryotic cells. The special chemical structure of this class of lipids results in many unique physicochemical properties and biological functions. The essential role of cardiolipin in mitochondrial functions has been underscored through identification of a genetic disorder, Barth syndrome, in which mutations in an X-linked gene, *tafazzin*, induce an altered cardiolipin metabolism, precipitate mitochondrial dysfunction, and result in a striking skeletal myopathy, cardiomyopathy, and heart failure.

We have recently identified substantial alterations in cardiolipin content and its molecular species composition in diabetic myocardium obtained from separate and distinct murine models of diabetes by exploiting our newly developed enhanced shotgun lipidomics. We have found that:

- 1) the levels of cardiolipin molecular species containing 22:6 fatty acyl chains, although initially diminutive, undergo substantial increases in diabetic myocardium;
- 2) altered cardiolipin metabolism occurs at the very earliest stages of diabetes in models of both type I and type II diabetes;
- 3) the temporal course of altered cardiolipin metabolism occurs either prior to or in parallel to triacylglycerol and acylcarnitine accumulation;
- 4) these alterations in cardiolipin molecular species are not due to changes in the molecular identities of lipid substrates involved in *de novo* cardiolipin synthesis.

**To identify the underlying cause(s) and the causal roles of the altered content and/or composition of cardiolipin molecular species**, we have demonstrated that activation of multiple calcium-independent phospholipase A2 (iPLA2) isoforms is present in the diabetic heart. Since hydrolysis of cardiolipin by iPLA2 is the first step of the cardiolipin remodeling process, activation of these enzymes could cause alterations in cardiolipin molecular composition if transacylase/acyltransferase activities are not activated in parallel. We have subsequently demonstrated the role of iPLA2 in the altered cardiolipin profile and the causal effects of the activated iPLA2 activity on mitochondrial dysfunction by using specific murine genetic models.

In addition, detailed comparisons of biosynthetic lipid substrate pools and positional specificity of cardiolipin molecular species have indicated that transacylation/acyltransferation of fatty acyl chains from mitochondrial phospholipid pools could be the likely source of alterations in the observed cardiolipin present in diabetic myocardium. Collectively, our research has demonstrated that alterations in cardiolipin content and composition underlie mitochondrial dysfunction in the diabetic state and provide important insight into the pathogenesis of Barth syndrome.



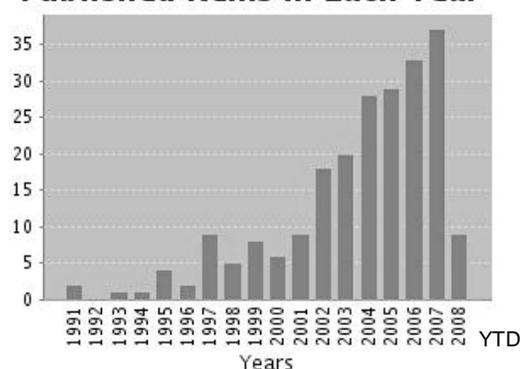
## The scientific and medical community is paying more attention to Barth syndrome!

The graph to the right depicts the number of peer-reviewed articles mentioning “Barth syndrome” as keywords in a search using the ISI Web of Knowledge database.

*Note: 2008 reflects January—June YTD*

*(The tafazzin gene was discovered in 1996)*

Published Items in Each Year



# Will Power Works—A Worldwide Project for Barth Friends and Family

By Louisa Malkin, Extended Family Member, Massachusetts, USA



Three weeks ago, I was lying in bed in Massachusetts wondering what on earth I could do to help my cousin Will and his family as he faced at least three rounds of surgery for Barth-related issues in New York. His surgeries all had to do with the fact that he has received the bulk of his nutrition for the last year through a central line called a port-a-cath and has gotten several infections. Will, who is one year my senior, has always been my trusted friend, advisor and partner in crime. As I sifted through memories of summers spent in Michigan, it was clear that Will gives us all so much; there must be something I could do for him!

Suddenly, I came across a particularly powerful memory. When I was still in grade school, a letter addressed to me arrived in our mail box in London. Mum looked at the stamp and announced that the mysterious epistle had flown all the way across the ocean from America! This was so exciting! I

immediately gathered all three of my younger sisters (a reliable and adulatory crew) and after appropriate pomp and circumstance, my mother carefully sliced open the envelope so I could pull out a handmade card. Admiring the originally-shaped hearts drawn with magic marker on the gray construction paper, I opened the card and read the message aloud: "Dear Louisa, I love you!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!! Love Will."

As I thought back to that letter, I realized it was the first time I had understood the power of a written message to convey affection and attention. As always, my big cousin Will was teaching me through his own example; the homemade card had been simply one afternoon's art project, yet that stampede of crooked exclamation points had made a huge difference to my whole life. As I realized how much Will's letter had meant to me, I extrapolated the idea and decided to reciprocate Will's thoughtfulness by sending him a letter...

The seeds of Will Power had been sown, and thanks to e-mail and digital cameras, the project grew incredibly fast. I contacted everyone outside the Barth community I could think of who knew my cousin (since I knew that the strong and close Barth "family" already offers great and constant support to each other). My mission was to show his whole family, and especially Will, that we are rooting for them all the way and that we are here for them as a network of support, love and friendship. Most of all, my goal was to make them laugh!!! I asked everyone to somehow create a "W" in photos of themselves, their families and their pets. I encouraged people to be ambitious, wacky, goofy and creative. Most importantly, I asked them to spread the word about Will Power.



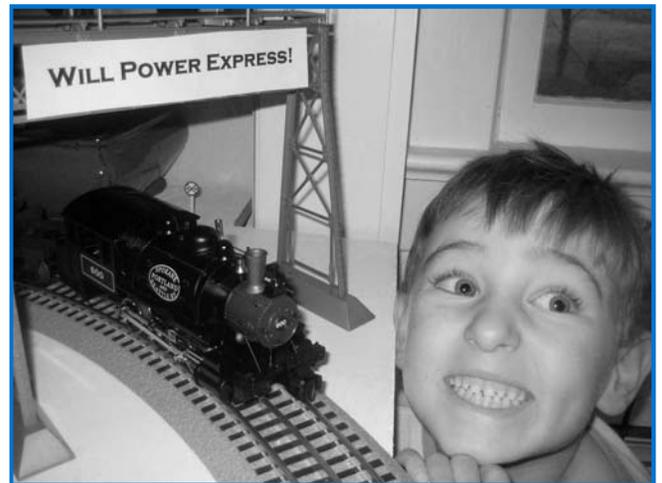
Will's friends and family responded with more enthusiasm than I had even imagined. I had no idea how successful this Barth project would be; the response was astounding and immediate! E-mails and photos came flooding in from all over the world: Texas, Beijing, Chicago, London, Boston, Johannesburg, Jerusalem ... it was truly inspiring. We received scores of creative photos, including many in which people held up their fingers and hands to display a W, one of an entire college lacrosse team whose players held up their sticks in the shape of W's, one of W-shaped twigs, and several of families curled up and stretched out on the floor to spell out Will's name in person. The challenge facing Barth boys and their families can be dispiriting for all involved, requiring great strength and courage. Will Power has shown one way we all can join the fight!

(Continued on page 21)



*(Continued from page 20)*

Will was discharged from hospital only two days ago, so he was there for more than a month. We learned of his triumph from my aunt through the email "grapevine" and in her message she said, "Thank you all SO much for your truly wonderful messages of support and your unending positive thoughts. Will Power worked! And I am sure that Will will continue to improve now that he can sleep in his own bed and have his dog nearby." I encourage you all to initiate your own "Power" campaigns when the going gets tough, because there is no easier and more exhilarating way of supporting our Barth friends and family. Sometimes the greatest things really do start small.



# Barth Syndrome Foundation of Canada—Outstanding Success

By Lynn Elwood, Chris Hope, Lois Galbraith, Barth Syndrome Foundation of Canada



*BSF of Canada executive walks on water!*

As expected, 2007 proved to be a busy and productive year for us. We have worked hard to grow our base of volunteers, and success in that endeavour has helped us to grow in all of our program areas. We have an amazing team of enthusiastic people working together.

Our financial situation in 2007 remained quite strong, and our budget for 2008 effectively plans for allocation of a significant amount of our reserve in order to fund Science & Medicine initiatives in 2008. We will need to foster growth in our fundraising efforts in order to sustain larger funding projects like the Scientific grants and conferences.

As we grow, we also change. This spring one of our founding members, Karen Gordon, retired from her position as Secretary on our Board of Directors. Karen was one of the original group who sat around the table and bravely decided to jump into forming an

affiliate organization within Canada. Throughout the six years Karen has been on our Board and Executive she has brought a fresh perspective, always keeping our families in focus and bringing her personal passion to the job. Karen will continue to work with us as a volunteer. Thank you, Karen, for all you have done and continue to do with us.

Susan Hone, an Executive member for the past two years, now joins our Board of Directors as our Secretary. Susan is a “Barth mother” who faces every challenge with enthusiasm. Her common sense and tenacity, as well as her past charity experience lead her to bring new and interesting ideas to the group. Susan’s organizational skills make her a great choice as the BSF of Canada Secretary to the Board. Welcome, Susan.

Our Board will also be joined on an occasional basis by some advisors: Paul Dickie, Marj Bridger, Bob McJannett, and Ian Morris. These are people appointed from our volunteer group who have particular skill in specific business or fundraising areas. They have agreed to assist the Board on an as-needed basis with specific issues in our longer term planning. We are pleased to have them join our team.

## Barth Syndrome Foundation of Canada 2007 & 2008

Looking back on 2007, we have to say it was a successful year. During 2007, in addition to our program areas, we focused both on raising much needed funds and adding critically needed volunteers. The result is that we have begun 2008 as a larger and stronger organization.

### The following is a summary of our 2007 financial status:

*(in Canadian dollars)*

2007 Revenue	\$54,794
2007 Expenses	<u>\$24,170</u>
Excess of Revenue over expenses before grant funding	\$30,624
Research grant funding	<u>\$23,278</u>
Excess of Revenue over Expenses	\$7,346

Opening Balance 2007	\$66,110
Excess of revenue over expenses	<u>\$7,346</u>
Closing Balance	\$73,456

*(Continued on page 21)*

(Continued from page 22)

As you can see we continue to have a healthy financial status. We have consistently exceeded our planned fundraising, underspent on expenses and have built up a surplus of funds over the years. This has put us in the fortunate position of being able to allocate additional funds to the Science & Medicine program in 2008, which has a planned budget of approximately \$65,000. The following is the summary of our budget for 2008. Please see below for background on the Science & Medicine plans.

Planned Expenses (including grant funding)	\$112,500
Planned Revenue	<u>\$72,000</u>
Planned Net Revenue	(\$40,500)

The year 2008 has already begun on a high note, with a number of events and the beginning of our annual appeal campaign. We held our Annual General Meeting in April 2008, and as was mentioned in the opening paragraphs, we have a few changes in our group. The following is our current Board of Directors:

Lynn Elwood, President  
Cathy Ritter, Vice President  
Chris Hope, Treasurer  
Susan Hone, Secretary

Lois Galbraith, Executive Assistant to the Board  
Board Advisors: Paul Dickie, Bob McJannett, Ian Morris, Marj Bridger

The following make up our Executive group which work on the daily activities of the organization and spearhead initiatives with our other volunteers. In alphabetical order: Lynn Elwood, Lois Galbraith, Chris Hope, Susan Hone, Cathy Ritter, and Carol Wilks. It is a pleasure to work with both of these teams!

## Science and Medicine

The 2008 year in our Science & Medicine program is a very exciting time. This year we are fortunate to be involved in the funding of two scientific grants with Canadian researchers. We are fully funding the following grant:

Richard Epan, PhD, McMaster University, Hamilton, Ontario

Title of Project:

***Consequences of the alteration of cardiolipin structure on the properties of the mitochondrial membranes***

We are also providing 50% of the funding for the following grant:

Christopher R. McMaster, PhD, Dalhousie University, Halifax, Nova Scotia

Title of Project:

***Synthetic genetics towards understanding Barth syndrome cell biology***

We are very pleased to be able to provide funding for these Barth syndrome related grants, as recommended by the Scientific and Medical Advisory Board. For a summary of the main focus of these grants please see pages 8-9.

We are also participating in the promotion of Barth syndrome science by providing funding for 2-3 Canadian scientists to travel to the 4<sup>th</sup> International Scientific, Medical and Family Conference in Clearwater, Florida in July this year. It is great to be supporting the efforts and enthusiasm of our Scientific and Medical group as they work towards research to help our boys.

Other efforts planned in our Science & Medicine program in 2008 include: producing a Canadian version of the Science & Medicine brochure, informational mailings to physicians in particular disciplines, and forming relationships with some physicians and other medical organizations for the purpose of providing guidance to us in medical areas.

(Continued on page 24)

# Barth Syndrome Foundation of Canada—Outstanding Success

(Continued from page 23)



*(L-R) Ryan, Adam and Robert patiently waiting for French fries!*

## Family Services

We continue to support, educate, and advocate for our affected individuals and families as much as we can, while always on the lookout for potential members.

The resource binders with Fact Sheets have been sent out to affected individuals and their families, and we hope that they are able to make good use of them when needed. We encourage recipients to give us feedback, both positive and negative, as well as give us suggestions for future information.

After the business portion of the Annual General Meeting was taken care of, it was time for our Family Outreach to begin. The family networking, socializing and relaxing are an important part of the day. It

was wonderful to just sit, talk, eat and relax together. Veteran parents were able to compare notes about their children and parents of younger children were able to ask questions. Talk did occasionally drift away from the disorder and non-Barth conversation was able to take place, while the affected men could forget all about Barth syndrome, and just hang out at their own dinner table.

## Awareness

The understanding and knowledge that doctors cannot diagnose Barth syndrome unless they know about it has given us the motivation to step-up our medical community awareness program. When going to their doctor visits or visiting and volunteering at hospitals, many of our volunteers take a packet of information to hand out to doctors and nurses. This one-on-one approach not only gives a real personal touch to the message, but hopefully makes it a lasting one.

On a wider and more targeted scale, we recently had a very successful country-wide informational mailing to geneticists and genetic counsellors. We have received a record number of replies, with positive feedback. Most of the responses have thanked us, said that they had not heard about Barth syndrome before and that they have not had a patient with Barth syndrome in their office. Several said that while they had heard about the disease, they were not well informed and were grateful for the additional information we provided. We feel confident that we have made a small but significant impression and that in the future these doctors will remember to check for Barth syndrome should the symptoms warrant it. Due to the success of that endeavour, we are planning another campaign this time targeting paediatric neurologists across Canada.



## Speed-O-Rama Car Show—Clearly a Classic for Barth!



*Lois Galbraith and Bob McJannett share a quiet moment at Silent Auction.*

**W**hen a Barth supporter sees a new avenue for fundraising and awareness, even a speed car show is game.

Bob McJannett, car guy and friend of the Barth Syndrome Foundation of Canada (BSF Ca), has new, fresh ideas and he is always thinking about Barth syndrome.

He has emceed our golf tournaments, sponsored our luncheon, attended our Annual General Meeting and donated much time and money. What else could one person possibly do?

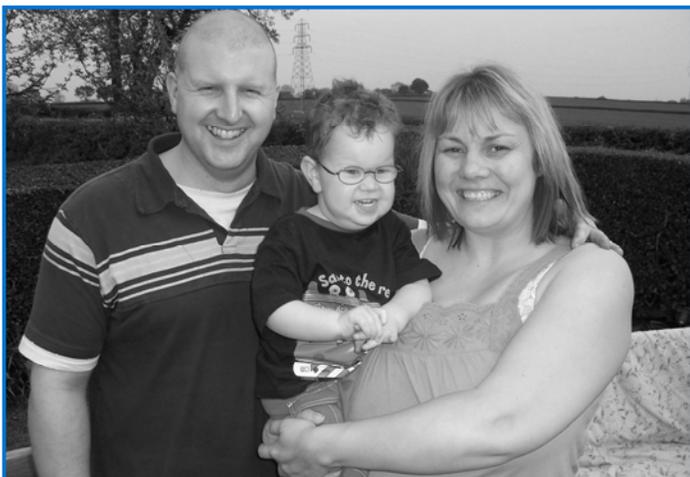
In the frenzy of cam shafts, beautiful women, after-market car products, perfect paint jobs and big engines, Bob organized a silent auction for the BSF Ca. He auctioned off tire rims, purple motor oil, welding helmets and car appraisals—all things foreign to us!

Car friends of Bob's donated prizes and then came to support him in this new event. The night raised \$3,150 and exposed a totally new group of people to Barth syndrome. Bob has new plans and ideas for the next Speed-O-Rama in Toronto in 2009. Yes... fast and fancy cars can drive the BSF Ca!



# Our Very Special Boy

By Julie Barratt, Mum of Affected Child, The Midlands, England



**O**ur story starts on 30<sup>th</sup> March 2005 when our son, Dillon, was born by caesarean section at 7am. He wouldn't cry and would only open one eye at a time, as though he was very tired after two days of on and off labour. The nurse said he was very cold and took him off to the Special Care Baby Unit. I didn't get to see him again until 3pm. The next morning at about 6 am a nurse came and told me that the doctor thought Dillon had a heart condition, and that they would be sending us to Leeds General Infirmary to be seen by a heart specialist. Little did we know that we would be there for three months and Dillon would be assessed twice at another hospital for a heart transplant.

I remember the day very well when they said Dillon might need a heart transplant. It was the Saturday after he was born—he was just four days old. We just sat there not saying anything, and I waited until they left the room before I cried my eyes out. When Dillon was 10 days old we were transferred to the Cardiac Ward, but two days later he collapsed and we ended up back in Intensive Care for five days. Dillon's heart gradually got much stronger as time went on, and they mentioned that magic word "home" when he was about eight weeks old.

It was June 2005 when we got him home on eight different medicines five times a day, and he had to be fed every two hours by naso-gastric tube, as well as a pump overnight.

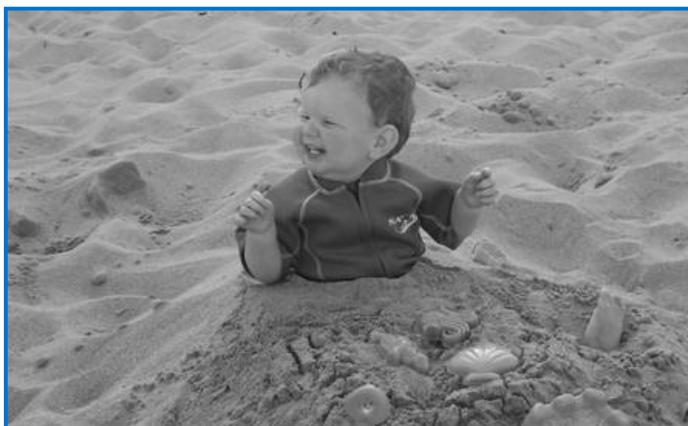
Two months later I found out I was pregnant again and eventually found out it was a boy. Unfortunately, we lost Logan James at 37 weeks; he was stillborn. We were then referred for genetic counselling. I knew in my heart that Dillon's problem was genetic. My Mum lost a boy two hours after birth with a heart condition and my Grandma lost four boys.

As Dillon's heart grew stronger, our attention turned to the rest of his body; in particular he was floppy with weak muscles. He also suffered from bouts of diarrhoea and lots of vomiting. They sent off some tests and these came back with some very high results in his urine, so we were referred to a metabolic specialist at Sheffield Children's Hospital. When we saw him in July 2006 he asked us lots of questions and then said, 'It sounds like he may have Barth syndrome.' 'At last,' I thought, 'I knew I was right!'

When we got home we looked up 'Barth syndrome' on the Internet and found the information we needed. This was it—it had a name. I didn't want to contact the sites until we knew for sure that he had Barth syndrome. We were told in February 2007 when Dillon had a regular check-up with the metabolic specialist, but it was not until August 2007 that it was officially confirmed by letter that he had Barth syndrome.

In February 2007 we contacted the Barth Syndrome Trust. It was heaven to finally speak to someone who understood. Dillon and I went to the Barth Clinic in Bristol in July 2007. (Scott couldn't come as he was rushed to hospital with appendicitis.) We met other families and also Dr Steward who knew what Barth syndrome was! I didn't have to explain it to him; he answered our questions!

Today Dillon is doing well with his heart and has come off all his heart medicines. He is on a low grade antibiotic as he has periods of neutropenia. He still totters about like a toddler and has just discovered the games 'Chase me' and 'Hide and Seek'. He has a very infectious laugh which makes everyone else laugh with him, and he adores animals. All in all he is a very special boy to us and we wouldn't change him for the world.



*The joys of sand! Dillon—age 3*

# Barth Syndrome Trust: 2007—A year of progress brings vital hope and energy

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

From an honest point of view, 2008 has not been a good year for us all so far. We have felt the loss of a loved one in the Barth syndrome community and we have worried while many of our boys and young men have struggled with ill health. It seems somewhat inappropriate to focus on past achievements when it is painfully obvious that we need to do more. And we need to do it now.

It is a testimony to the calibre of people involved in this group that, once a goal is accomplished, our focus moves quickly to the next step. Our efforts remain firmly fixed on the present and the future. So in our summary, you'll see that we have some plans mapped out for the year ahead, plans which are already well under way. However, it is equally important sometimes to look back to see what our efforts have accomplished. The realisation of progress made brings with it vital hope and energy. I would like to thank our families, volunteers, doctors and scientists for their committed, intelligent and compassionate support. Without you, this progress would never have happened....

## Main Achievements in 2007

### Awareness

#### Mailing to Cardiologists

The BST medical brochure, first printed at the end of 2006, has been distributed to all the cardiologists in England, Scotland and Wales likely to come across children with Barth syndrome.

#### EURORDIS Project

In July, Michaela Damin represented the UK as the Genetic Interest Group delegate at the European Organisation for Rare Diseases (EURORDIS) Conference in Prague for the Rare Disease Patient Solidarity Project (RAPSODY). The establishment of centres of expertise for rare disorders was explored and gained momentum. These centres will ensure that those

affected by these disorders, including Barth syndrome, will receive the best care possible.

#### Working with the Genetic Interest Group (GIG) and Jeans for Genes (J4G) on a Family Route Map Project

The Barth Syndrome Trust was one of only six charities selected for this project. Together with GIG, we have created a vital Family Route Map for all

those affected by Barth syndrome. This booklet serves as a signposting system to access appropriate information and services in the UK. It is now being distributed to affected families, genetic centres and healthcare professionals. Other groups have asked us to help them create Route Maps for their condition.

#### Working with the Children's Heart Federation (CHF)

Our work with CHF continued in 2007 with Michaela Damin attending various meetings as a Council Member. The AGM and Annual Conference were held in York, and topics included the causes of congenital heart disease, advances in paediatric cardiology, and the Every Disabled Child Matters Campaign. Workshops focused on disability rights and supporting bereaved families. Our thanks also go to CHF for giving a "Barth family" a weekend break. Julie and her son Dillon thoroughly enjoyed their 2-night stay in Chester and their visit to the world famous Chester Zoo.

#### Family Services

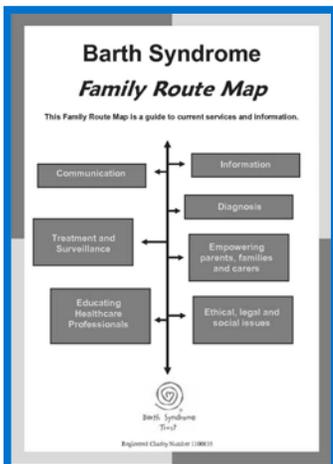
Our Family Services teams in the UK and Europe are in regular contact with families providing empathy, support and information.

#### European Gathering

Annick Manton, as head of Family Services, attended a gathering of Dutch-speaking families in Belgium. The families enjoyed meeting and comparing notes. They were given copies of the Family Services booklet which was updated and translated for the occasion by Jo van Loo and Hans v.d. Riet.

#### UK Family and Volunteer Gathering

The gathering was held at the Avon Valley Country Park on 7th July, the day after the Barth Syndrome Clinic in Bristol. Families relaxed, exchanged notes and asked questions resulting from the Clinic. Volunteers and friends of the Trust joined the families for the day.



(L-R) Marco Damin, Dr. Colin Steward, his wife Christine, and daughter, and Michaela Damin at UK Family and Volunteer Gathering.

## International Conference

Each family was sent a DVD of the family sessions of the 2006 International Barth Syndrome Conference. Families were invited to take part in a draw for £2000 travel assistance to the 4<sup>th</sup> International Scientific, Medical and Family Conference on Barth syndrome in Florida, USA, 21<sup>st</sup>–26<sup>th</sup> July 2008. The lucky winners were the Carvalho family from Portugal.

## Science and Medicine

### Barth Syndrome Trust Funds Research Project

The Barth Syndrome Trust contributed to the funding of two separate research projects in 2007. One such project was the establishment of a new diagnostic test for Barth syndrome. We are delighted to announce that this test is now available—it only needs one drop of blood on filter paper which can be posted to the laboratory for analysis. It's fast, cheap and easy to arrange. **This is an excellent example of how our fundraising efforts can benefit affected families throughout the world!**

### Dedicated Barth Clinic

Our annual clinic with the Bristol Royal Hospital for Children was held on 6<sup>th</sup> July. Families from all over the UK attended. Affected children were evaluated by experts, and a bank of data about the syndrome is being compiled. Parents had one-to-one meetings with the doctors and an open group discussion in the afternoon. Dr Willem Kulik from Amsterdam provided an update on his current research into the development of a screening test for Barth syndrome using bloodspots and tandem mass spectrometry.

### International Barth Syndrome Medical Database and Biobank

Families from the UK have already been enrolled, with plans underway to enrol European families next. This is an international project with participation from countries around the world. By increasing the number of patients enrolled in this Registry, we will gain a better understanding of the natural history of the condition. Research will also be stimulated as we are now able to provide researchers with the data and samples needed.



*Kai, age 6, at the 2007 Barth Clinic*

## Fundraising

### Our grateful thanks go to all volunteers and donors in 2007.

Families, volunteers and friends arranged a number of fundraising events in the UK and Europe. Static collecting boxes proved to be a consistent source of income. We were also fortunate to receive individual donations, grants and in-kind donations from various organisations and businesses throughout the year—please see the list of donors at the end of this Newsletter.

## Publications

The Publications team works closely with the Barth Syndrome Foundation in USA to help produce this Newsletter and to collaborate on other material such as brochures. They have supported all BST programmes and events during the year with appropriate literature, information packs for new families, posters and documents.

## Volunteers

Since BST is run entirely by volunteers, one of our key aims is proper communication and training for all our volunteers. Our workshops are an ideal opportunity for this as well as to ensure that we are meeting their needs.

### UK Volunteer Workshops

#### **Two workshops for volunteers were held in 2007:**

During the workshop in March 'seasoned' volunteers were given strategies and guidelines to help them communicate more confidently about Barth syndrome and the work of the Trust. Potential volunteers came from as far as Wales and Derbyshire to attend the second workshop in November. Among the newcomers were six affected families. Discussion of their needs and expectations gave a new perspective on our plans.

*(Continued on page 28)*



*BST volunteers are eager to help!*

# Barth Syndrome Trust: 2007—A year of progress brings vital hope and energy

(Continued from page 27)

## Looking Ahead—Our Plans for 2008

- Fund new research projects in the UK and Europe
- Fund various doctors and scientists from the UK and Europe to attend the 4<sup>th</sup> International Scientific, Medical and Family Conference on Barth syndrome in Florida, USA, 21<sup>st</sup>—26<sup>th</sup> July 2008
- Hold our Annual UK Clinic and Gathering in Bristol, 19<sup>th</sup>—20<sup>th</sup> September 2008
- Organise a European Gathering in The Netherlands or Belgium
- Send awareness posters to hospitals throughout the country
- Enrol Dutch-speaking patients into the International Medical Database and Biobank
- Distribute the Family Route Map nationally
- Distribute new information packs to the medical profession
- Finalise our Volunteer Handbook
- Find partners (through grant-making organisations and individual funders and fundraisers) in order to achieve our stated objectives
- Help each family in the UK create an Emergency Care Plan
- Revise the welcoming pack of information for new families
- Continue translating our literature into European languages starting with German, French, Italian and Spanish

## Receipts and Payments Accounts

	Year 31 Dec 2007	31 Dec 2006
Receipts	£19,028	£29,044
Payments	£32,622	£8,892
Net	(£13,594)	£20,152
Cash Funds this year end	£37,800	£51,394



## Hello from Holland!

I'm Justin from The Netherlands. I am almost 16 years old and I have Barth syndrome. As a baby of 4 months old I became terribly ill. My small intestine slid into my large intestine and they discovered that my heart was so enlarged that it

was as big as an apple. After treatment, further research was done. The outcome was that I had cardiomyopathy. I didn't grow well and ate badly. Everything was put down to bad nutrition....

Many years later, after my last year at elementary school, they searched for the reason for my bad eating and poor growth. In July 2005 after genetic testing, the outcome was that I had Barth syndrome!! Everything became clear for me and my father and mother; the puzzle was completed. (It is not hereditary but a spontaneous mutation in me).

At school it became more difficult because I missed a lot of classes because of lack of energy and nausea. In May 2007 after consultation I got a P.E.G. feeding tube and it helps. I gained 9 kilograms in weight in one year and grew 12 centimeters taller in less than a year!!! I'm doing reasonably well at the moment.

I seldom miss school now and I am never nauseous anymore. Before, I was nauseous regularly because I always felt full. I am in the second class of secondary school and want to become a car mechanic. Maybe it won't be possible full-time, but I'm going to try. Working part-time is a possibility too.

My hobbies are putting things together, football (soccer), computers and I love my dog and cat!!!!

Once a year we have a meeting with all the Barth families in Holland and Belgium and last time Annick was there too, which was fun!! I was asked to write this and was very happy to do it. Warm greetings from The Netherlands!



# In Memory of Michael

By Philip Reece, Father of Beloved Son Michael, Australia



**M**ichael was born on the 11<sup>th</sup> January 1998 at the Mater Hospital, Crows Nest. Carolina and I were filled with pride and joy – our family had begun.

At three days old Michael was struggling physically. Michael had an enlarged heart and was going into heart failure. After two weeks of stabilising medication the three of

us went home with an outlook that did not look good. As we left the hospital, a special care nurse confirmed the reality of our situation; her parting words were, “Enjoy him while you can, live one day at a time”.

At home the life of a new family started, but with the added dimensions of medications and Michael's inability to feed and thrive. Carolina would cajole every bit of food into him, trying to keep his weight, strength and health up.

With the help of grandparents, family and lots of friends we were supported through those first harrowing years. We also had lots of support of Michael's wonderful doctors, nurses, therapists and so many others too numerous to mention. Time and time again he confounded his doctors by going into a dip in his heart condition, then to somehow emerge.

After two and a half years and a few periods of hospitalisation, Michael was diagnosed with Barth syndrome. We now had an explanation for a lot of things that affected Michael's every day life.

After a further time Michael began to walk and talk. This is when his shining personality began to emerge. BOY! didn't Michael's talking take off. “Michael be quiet for a second and listen,” would become a phrase heard thousands of times in our house over the years.

The biggest day-to-day worry for Carolina and me was how little Michael ate and his inability to keep down what little he did eat. Carolina worked out her own ideas and ways to get Michael to eat, taking clues from the Barth syndrome families who had oddly noted a liking for strong flavoured foods amongst the boys. So began what Carolina and I called Michael's love of gourmet foods. Another love of Michael's was cooking videos, which we all watched every chance we got.

After four years of juggling doctors, physio and other therapy we were lucky enough to get Michael into Gumnut Preschool at Narrabeen. After a wobbly first three months there Michael's social abilities suddenly took a step up. He used his charm and chatter, overcompensating for his physical limitations, to make his presence felt in that environment for the next two years.

In 2003 Carolina and I began looking for a school for Michael to attend in 2004. Numerous enquiries and fate led us to Our Lady of Good Counsel School (OLGC). We first met Mark Bateman and described our Michael to him. He straight away said he felt there was something OLGC could do for Michael. That was an understatement. Michael went on to enjoy the best and most nurturing four years Carolina and I could have hoped for.

To aid Michael's mobility around the grounds of OLGC, Michael used a black push-handled tricycle, which all the children would want to help push. Emily, Michael's Kindergarten buddy, Denise Egger or Chris Petry would have to curb the children's enthusiasm so as to restore order.

At the end of 2006 the school generously funded an electric bike with a grant from the Catholic Board of Education, so as to increase Michael's mobility and sense of independence. On his electric bike he took off like a shot.

OLGC's school motto, “Let your light shine,” impacted Michael. When he first started at OLGC he had hundreds of lights shine upon him. For a while he absorbed those lights, building up a light of his own inside himself which he then shone brightly upon others.

Carolina and I would like to sincerely thank Mark Bateman, Janet Agostino, Denise Egger, all Michael's teachers, all the people at OLGC school and church, and especially all the children who treated Michael with kindness and compassion allowing him to have a most joyful life.

Michael loved his cooking, swimming in Nanna and Pop's pool, his Playstation, his Harry Potter, his Star Wars, his handball, his ice creams, his grandparents, family, friends and most of all his time at OLGC.

We will all remember Michael's sense of humour, fun loving nature and beautiful smiling face. **Michael was my champion and Carolina's beautiful boy.**

His spirit will stay with us all forever, shining brightly and be deeply cherished by all who knew him.



## Sibling Spotlight

By Alanna Layton, Sister of Barth Individual, Florida, USA

Below 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:** Eden  
**Age:** 12  
**South West England**

**What are your hobbies?:** Warhammer 40k, Reading, Gaming, Badminton, Ju jitsu, Scouts.

**Affected sibling?:** Jack (20 months)

**What is your favourite thing to do with your brother?:** I like doing many things with my brother. A few favourite things are helping him to walk, reading him books and having a good old chat in baby language.

**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?:** Hey, their body may be weaker than normal but they still have a great mind and spirit.

**What does BSF/BST mean to you?:** They organise places where all the Barth kids meet and make friends, have a real laugh and get to know each other.



**Name:** Kristy  
**Age:** 16  
**Monahan, Texas, USA**

**What are your hobbies?:** I love to play volleyball and basketball! Also hangin' out with my friends a lot.

**Affected sibling?:** Benjamin (3 ½ years)

**What is your favorite thing to do with your brother?:** Anything! He always makes me smile and laugh! I guess my favorite thing to do with him would have to be going to get a snow cone.

**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?:** It may seem VERY scary and sad at first, but there are wonderful doctors out there that are able to help him.

**What does BSF mean to you?:** It's like a family. Everyone knows what you're going through and how it feels. It's all these people trying to help find a cure for my brother as well as others.



**Name:** Jennifer  
**Age:** 23  
**Regina, Saskatchewan, Canada**

**What are your hobbies?:** Ringette, Softball, Coaching, Reading, Spending time with my family.

**Affected sibling?:** Jared (14 years)

**What is your favorite thing to do with your brother?:** Everything, but if I had to pick one I would say laughing.

**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 offer them myself as someone who they could talk to about it and who may be able to comfort them with my own experiences.

**What does BSF/BSF Ca mean to you?:** BSF to me means always having a place where you are able to connect with other individuals or families for information or support whenever you need it. I think that it can also be like having a really large extended family because everyone is able to build such meaningful relationships.

We deeply appreciate the contributions of all the many donors who generously support our efforts in many ways through time, talent and treasure. Here we gratefully acknowledge donors who have made contributions from January 2007 through May 2008.

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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.barthsyndrome.org](http://www.barthsyndrome.org), and clicking on the 'How to Help' button on our home page.

### Employer Matching Programs

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.

(L-R) Danny (age 17) wearing Roby's badge on Roby's 18 birthday! ~ Western Australia



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Cook, Dave	Grenc, Ed	Malfara, Frank	Slepkov, Martin	
Cooper, Cindy	Haggett, John	Mann, James	Smolic, Alex	
Cooper, John	Haggett, Judy	Mann, Ruth	Souter, Caroline	
Cooper, Nancy	Hamilton, AnnMarie	Martin, Arther	Stabb, Susan	
Cooper, Rick	Hamilton, Glen	Masterson, Moira	Steamwhistle	
Cornthwaite, Hazel	Hamilton, Reg	McCurdy, Kate	Stevens, Mike	
Cornthwaite, Mike	Hamilton, Sam	McCurdy, Steve	Stitt, Barabara	
Coulson, Steve	Hamilton, Susan	McGill, Steve	Stoll, Brian	
Country Meat Cuts	Hammond, Bob	McGuinness, Celia	Storey, Dick	
Cowell, Chris	Hammond, Jean	McJannett, Andy	Storey, Janis	
Cox, Jerry	Hammond, Steve	McJannett, Bob	Stratford Motor Prod	
Cox, Patty	Hardie, Cathy	McJannett, Rob	Street Classics Cruise	
Cruise Holidays of Barrie	Hardie, Shane	McJannett, Susan	Sturupp, Penny	
Cummings, Jim	Harrington, Tina	McKee, Bev	Sunsational Landscapes Inc.	
Cummings, Marie	Hatfield, Louise	McKercher, Don	TD Trust Bank - Havelock, ON	
Damin, Marco	Havelock Belmont Methuen Library Board (Sandy Harris, Ron Gerow, Glenn Girven Sharon Howarth, Nancy Law Leone White, Lois Galbraith, Connie Whitmore)	McKercher, Ingrid	Tech Web Printing	
Damin, Michaela	Hill, John	McShane, Harvey	Thomas, Brian	
DaSilva, Theo	Hill, Rick	Megelink, Jasper	Thorpe, Jeanette	
Davidson, Alex	Hintze, Audrey	Megelink, Mary	Timleck, Barry	
Davidson, Bonnie	Hocevar, Frank	Mendes, Lynsi	Tjart, Gwen	
Davies, Barbara	Hocevar, Helen	Merrill, Debra	Tjart, Richard	
Davies, Diane	Hone, Barbara	MGM Insurance Agency Ltd.	Tomlinson, Annette	
Davies, Don	Hone, Chris	Millar, Margaret	Tomlinson, Brian	
Davis, John	Hone, Susan	Millar, Ronald	Tomlinson, Danny	
Davis-Hyder, Karen	Hope Aero	Miller, Pickard,	Tomlinson, Shannon	
Death, Barbara	Hope, Christine	Miss Classic Car Club	Toth, Matt	
Death, Wilf		Morris, Dianna	Tramp Warner	
		Morris, Elsie	Trillium Gift of Life Network	
		Morris, Ian	Trim, Norma	
		Morris, Les	Trim, William	
		Morris, Pam		

# 4<sup>th</sup> International Scientific, Medical and Family Conference Barth Syndrome: *On Track Toward a Cure*

“As a physician interested in the genetic basis of pediatric heart diseases, such as cardiomyopathy, my attendance at BSF’s conference was invaluable in learning about patients with this genetic disorder and about scientific progress into the mechanisms of disease and genotype-phenotype correlations.”  
~ Dr. Arnold Strauss, Cincinnati Children’s Hospital Medical Center, Cincinnati, OH



*Bly, age 4, is making sure we are all on board BSF’s track toward a cure for Barth syndrome!*

*(Continued from page 10)*

**The experience of being a part of a Barth syndrome conference can be encapsulated in one statement:**

***“You have to see it to believe it!”***

If you have not already registered with the Barth Syndrome Foundation for this Conference, please do so now! The Conference Committee has worked tirelessly to orchestrate this milestone event for the benefit of medical professionals and Barth syndrome families! Don’t miss your opportunity to be a part of this professional exchange and dialogue!

### **REGISTER NOW!**

**You must register with BOTH the Barth Syndrome Foundation and the Belleview Biltmore Resort & Golf Club!**

### **To register with the Barth Syndrome Foundation:**

Visit [www.barthsyndrome.org](http://www.barthsyndrome.org) and complete the 2008 Conference Registration form.

### **To register with the Belleview Biltmore Resort & Golf Club:**

Visit <http://www.belleviewbiltmore.com> (reference ‘Barth syndrome’ when making your hotel reservations); or call 1-800-237-8947.

***Saving lives through education, advances in treatment and pursuit of a cure for Barth syndrome***



**Barth Syndrome  
Foundation**

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

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