

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

### Highlights of Interest

- Success of Conference
- Letter from New Executive Director
- Why Barth syndrome is underdiagnosed

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## BSF 2008 Clearwater Conference Showcases Progress

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

In Clearwater, Florida during two days in late July, over 50 scientists and physicians attended intensive meetings about Barth syndrome (BTHS). The Scientific and Medical sessions featured 23 lectures, 17 posters, and 3 young men who spoke about their difficulties living with this condition. Topics ranged from the understanding of how the cardiolipin molecule functions to how the metabolism of BTHS individuals is altered. New data and unpublished reports were revealed, which reinforced the conviction that this was a special meeting

marked by openness and a free exchange of ideas among all of the participants. Many of the speakers were previous recipients of research grants sponsored by the Barth Syndrome Foundation and its affiliates. In addition, most of the lectures were available over the internet in real time (and available for reference for 3 months) using a webcast system. This biennial International Conference sets a high standard of accessibility for the patient and the scientific and medical communities.

*(Cont'd on page 4)*



*Photo by Amanda Clark*

## Family Sessions Offer Education, Hope and Fun

*By Susan Wilkins, Board Member, Barth Syndrome Foundation*

Life changing. It might sound a little dramatic, I know. But that is how I feel about the Barth Syndrome Foundation's International Scientific, Medical & Family Conference. And as I look at the pictures we have taken over the years of the conference, it takes my breath away. We started in 2000 on a wing and a prayer, three mothers who had never met each other face to face. We were driven to bring our Barth families together in the same room for a weekend in Baltimore. And we did it.

That first picture of our boys and the doctors and scientists who attended did not have very many people in it. But that first meeting in Baltimore was life changing for those of us living with Barth syndrome. Now, when I look at the picture of the families, doctors and scientists who attended our 2008 Conference this past July, I realize the impact of our Foundation. I am so happy to say that my family and I have been able to attend every one of the BSF conferences since that first gathering in 2000.

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# President's Letter

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



Success is not something that can easily be explained in the non-profit sector. In the truest form, success is accomplishing a planned or attempted effort. However, defining success as it relates to the Barth Syndrome Foundation (BSF) is not just about accomplishing a task. Our success is measured by the difference we have made. Recently, BSF has yet again been a leader. We saw a need, figured out a creative solution, broke new ground, and made a measurable difference. Here is what happened.

## International Barth Syndrome Conference

There is no program in this organization that has greater impact on our mission than our biennial conference. It is successful on all levels, and huge differences are made in many ways during this event.

Scientists are inspired by witnessing the remarkable spirit our families possess and by meeting the boys who benefit from their research. Families are empowered as advocates as their perspectives are not only heard but taken to heart. Relationships are forged and research collaborations are born. Ideas flourish. Commitment to the cause is deepened. Progress is made. An overwhelming sense of community is strengthened. This is what transpires at the conference. Attendees of all types consistently tell us how this event stands apart from anything they have ever seen, exceeding their expectations in ways they cannot even describe. This is what draws people back.

However, earlier this year we conducted a needs assessment. Those who had attended the conference unanimously recognized the value of this program. But there were obstacles that would prevent some from attending the event, despite how much it meant to them. We learned that some families could not afford to come to the conference and some of the boys with BTHS were simply too ill to travel. We learned that some clinicians entrusted with the care of a patient with Barth syndrome could not justify closing their practice for several days to attend a meeting that only affected one of their patients.

The vulnerability that comes from barriers to information is no less a concern than that which once stemmed from being isolated. There were obstacles that would prevent some from coming to Clearwater, and there had to be a way we could help.

## Travel Funding

BSF is not permitted to provide individual funding to patients or their families, but we can serve as a link to private sources that can offer that support. This way we were able to secure the resources for every family who let us know (in confidence) that financial aid was needed in order for them to be able to come to the conference. Selflessly, individual donors who would not receive a tax credit contributed air miles to get attendees to the event. Others privately paid for rooms to cover lodging expenses. In the end, everyone who spoke up was able to be there. It was amazing!

## Web-Ex

Another challenge was to ensure access to the information being presented to families who could not come to the event because their child was too ill to travel and to doctors and scientists who could not justify taking the time off from work to attend our conference in person. The full benefit of attending could never be gained since there is so much that transpires on so many levels, but at least we could offer part of the experience remotely. We needed those who could not attend, and they needed us. An idea emerged... "What if we broadcast the event over the web?" From that idea a plan was born.

(Cont'd on page 3)



For several months, we investigated various E-based meeting platforms that would provide scientists, doctors and families alike with a vehicle to listen to the educational sessions and have the ability to ask questions from anywhere around the world. Once again we found ourselves doing something that no other rare disease group had done before us. There were no models which we could reproduce. It was up to us to figure it out.

It was certainly an all-hands-on-deck effort. Long before the 2008 Conference occurred, we were going through a systematic process of finding the right platform. We had to go to the conference venue to test various platforms. We recruited volunteers as our test subjects to evaluate these platforms. Anything could have gone wrong, but we never gave up (as our organizational values dictate)!

Later, we were down to the wire, scrambling to obtain permission from the presenters to include their presentations in this unprecedented program and to work out several technical glitches. In the end, we were able to transmit our educational sessions to doctors, scientists and families all over the world. It was quite an amazing feat. There were many people involved in reaching this historic milestone. Had it not been for the presenters understanding the overwhelming benefit of this approach and providing their permission to allow their presentations to be included, we would not have had a program to share. Had it not been for the volunteers who went through the on-site training to work through the details and monitor the sessions as they were happening, it would not have worked.

Despite the overwhelming support for offering this new feature of our conference, success could not be guaranteed as it would depend upon who accessed the system. As the conference began, people began steadily to log on. As of July 30<sup>th</sup>, 174 people either attended the web-based conference live or logged on to listen to the sessions after our conference had concluded. That was when we knew we had made a difference.



## Family Sessions Offer Education, Hope and Fun

(Cont'd from Cover)



*Paula and Woody Varner's grandson presents the first-ever Varner Award for Pioneers in Science and Medicine to Dr. Peter Barth and Dr. Richard Kelley, who have made a positive and lasting impact on Barth syndrome.*

The most recent Conference in Clearwater was superb in every possible way. There were more of all the good things we need to make this gathering and our Foundation a success—which translates into the number one most important goal for our sons—more help!

### Barth Syndrome Clinics

The first several days of the Conference were dedicated to the clinics, which are my favorite part. They were held in the huge ballroom at our hotel, and each family had appointments with as many of the Barth professionals as they wanted to talk with one on one. Our own Dr. Richard Kelley was there, along with four wonderful nutritionists, Rhonda Avery, Carrie Crain, Linda Croxton, and Penny Porch Edwards who came with new diagnostic tools and suggestions for our sons. We had amazing OT and PT experts Karin Colby Watson, Jeanette Van Duyne and Bobbie King interacting with our sons to give suggestions about how to increase strength and range of motion and what particular body and muscle movements might

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# BSF Clearwater Conference Showcases Progress

*(Cont'd from Cover)*



*Dr. Iris Gonzalez and Dr. Colin Steward enjoy reacquainting at the Barth Syndrome 2008 Conference.*

One of the most intriguing questions in BTSH research is what does cardiolipin, a unique lipid that is altered in this disease, do? Dr. Haines presented his idea that the cardiolipin molecule functions to help the movement of hydrogen ions in the mitochondria, the energy-producing part of the cell. Drs. Schlame and Carboni showed that while cardiolipin abnormalities are closely associated with BTSH, there are some patients who have normal cardiolipin levels; an observation that challenges the traditional scientific view. Dr. Jensen reminded us that there is a Barth-like disorder, a mitochondrial disease which shares many of the specific symptoms of BTSH, that also does not show this cardiolipin deficiency. As we discover more and more about the interplay between tafazzin (the gene altered in BTSH) and cardiolipin, we need to constantly update our scientific/medical perspectives to place us in a better position to find an effective treatment.

that not all of these individuals are diagnosed with BTSH which is surprising given what we know about this gene. Dr. Steward's experience in Bristol, England suggested that a large number of unexplained fetal deaths may be due to tafazzin mutations. Dr. Kulik presented the cardiolipin bloodspot assay which greatly expands the number of individuals world-wide who can receive a diagnosis in a timely and cost effective manner. Susan Kirwin showed how the specific gene test for BTSH may not be able to identify all cases of BTSH. These observations point to a continuing need to broaden the target population for diagnosis, while improving diagnostic criteria, techniques and support.

Dr. Lipshultz revealed that in the Pediatric Cardiomyopathy Registry, tafazzin mutations are clearly represented. However, he also stated



*Dr. Ariel Sherbany and Will (age 22) enjoy the Luau social event at the Barth Syndrome 2008 Conference.*

Understanding the precise function (or functions) of the tafazzin gene is also vital. Drs. Acehan and Claypool showed how tafazzin dysfunction alters the mitochondria, and Dr. Gottlieb explored how this related to cell death. Dr. Vaz measured tafazzin gene expression, with its several variant messenger RNAs, and found it in most animal tissues with its greatest concentration, surprisingly, in the pancreas, spleen, and liver as opposed to the heart or muscle tissue. Dr. Han, who is studying the relationship of diabetes and cardiolipin, showed that the quality of cardiolipin found in the mammalian brain resembles that found in the heart and muscles of BTSH individuals. Dr. Han also linked the idea of cardiolipin quality with thermogenesis, an intriguing hypothesis. These presenters show how the impact of BTSH research extend beyond the immediate goal of helping our boys and into areas relevant to more common health problems such as diabetes, obesity, and perhaps certain cancers.

Dr. Spencer covered some of the prodigious amount of work that has been done in getting the BSF-University of Florida Medical Database and Biorepository up and running. Drs. Spencer and Cade showed that the metabolism of BTSH individuals is altered such that they are unable to extract oxygen from the blood for use in their muscles during exercise. Data collected by Drs. Spencer, Cade, and Bryant at the Cardiac Clinic held at this year's Conference were even more extensive than in previous years and will be essential for finding and validating new treatments.

These clinical data and the Barth Syndrome Medical Database provide important tools in finding and in evaluating promising new ideas for therapy. New ideas such as the use of caspase-specific inhibitors, which Dr. Aprikyan showed, may reverse the effects of a tafazzin dysfunction in white blood cells. Another new idea was proposed at the Family Sessions by Dr. Kelley who found an arginine deficiency in BTSH individuals using information obtained from the Conference's Clinic just two days before! Inhibition of calcium-independent phospholipase A2, an enzyme that modifies cardiolipin, was suggested by Dr. Ren as a

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*Our Roaring 20's social event, which brought together our clinicians, physicians, researchers, families and volunteers, was an evening of getting acquainted and having fun! Here are a few of our docs on the dance floor!*

potential area for drug development because it reversed some of the mutant properties in his fruit fly model of BTHS. Dr. Greenberg found that yeast mutants that are defective in cardiolipin have a reduced lifespan, but treatment with a class of compounds known as p38 inhibitors may be able to reverse this lifespan reduction. Dr. Sparagna spoke about using delta-6-desaturase inhibitors and safflower oil to reverse the heart defects and cardiolipin problems she observed in a rat model of heart failure. These therapeutic ideas still need more work to fulfill our ultimate hopes, but their discussion at this biennial meeting shows the progress that has been made.

Many of us are still catching our breaths from the new ideas and unique observations revealed at this remarkable Conference. The hypotheses that were generated and the communication among the new and the familiar faces of the BTHS research community will pay dividends. The quality of this and previous BSF conferences validates the excitement and the progress that has been made and encourages us to look forward to our next meeting scheduled for July 26–31, 2010 in northern Florida.

## 2008 Conference Attendee Testimonials



“The quality and the broad spectrum of scientific presentations at the International meeting of the Barth Syndrome Foundation was very impressive and truly extraordinary. Participation of many outstanding and enthusiastic scientists studying Barth syndrome provided a unique opportunity to closely discuss most recent findings and to plan new, more comprehensive collaborative studies aimed at understanding the pathophysiology of Barth syndrome. The active participation of many Barth patients and their family members and the opportunity of informal interactions with them created a truly unique atmosphere and made this meeting even more exciting and invigorating. Hearing personal stories of the patients and their family members, and learning more about the issues they are dealing with on a day-to-day basis, provides unforgettable energizing incentives to keep focus on understanding the cellular and molecular mechanisms of Barth syndrome and elucidating potential novel therapeutic strategies.” ~ *Andrew Aprikyan, PhD, Division of Hematology, University of Washington School of Medicine, Seattle, WA, USA*

“We had no idea just how much of an impact the 2008 Barth Syndrome Conference would have on our family. It has opened up communication with our son and our other two children. They talk openly now about Barth syndrome and what it is like to not only have Barth syndrome but what it is like to be a brother and a sister of someone with Barth syndrome. A mother could not ask for more!” ~ *Julie Floyd, Georgie, USA*

“Once again the BSF Conference was a source of new and valuable information for our family. The physicians, scientists and various other professionals are truly interested in our children and are working diligently to find a treatment/cure for Barth syndrome. We came away from the conference with new information and ideas to share with our son's health care providers. Meeting and reacquainting with other families at the conference who are living with Barth syndrome helps make this “rare” syndrome seem not so “rare,” but instead it seemed like an extended family reunion. We feel very privileged to have found the BSF and attend the first class conferences they have held.” ~ *Susan Hone, Saskatchewan, Canada*

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

“The 2008 BSF Conference was our first and we didn't know what to expect. The warmth and friendliness of everyone was overwhelming. We came home with a wealth of information. It was an experience we'll never forget.” ~ *Leonie Godenzi, Western Australia*

“I joined some scientific sessions (unfortunately not all - prevented by official duties) and I was really enthusiastic about what BSF was offering. It was the first time that I had heard (and seen) a live transmission of a scientific conference - and I think it's worthwhile to do!” ~ *Dr. Helga Blaschke, Western Australia*



# Family Sessions Offer Education, Hope and Fun

(Cont'd from page 3)



lead to increased function and mobility. We even had our own private Cardiology clinic, complete with echocardiograms, EKG's, and the ever popular (*not!*) stress test for the older guys. It was so exciting to see research being done on the spot by our incredible pediatric cardiology crew, led by Dr. Carolyn Spencer, Dr. Barry Byrne and Dr. Randy Bryant. Neurological issues were checked and addressed by Dr. Ariel Sherbany, and our dynamic duo of Becky Kern and Dr. Iris Gonzalez helped us understand the many genetic issues related to BTHS. There was more collaboration between the professionals and the families than ever before.

There were also games, crafts, Nintendo playing, movie watching, therapy dog petting, and even napping going on inside the ball room as kids and families waited to see each expert.

The room was so full of activity, learning, sharing, questions, answers, laughter, talking, tears, listening, cooperation and camaraderie among the boys, young men, siblings, families, volunteers and experts. For a family like ours, who has been living with BTHS for 26 years, this part of the Conference is in a word...magic. These clinics are the living proof that there is *hope*, and that all these things will lead to answers for all our sons, since we know that all of the data collected during the clinics will be added to the growing Barth Syndrome Medical Database.

## Family Sessions

The next few days we settled in for the meetings, which are also my favorite part of the conference (really—every part of the conference is my favorite part!). The doctors and scientists had their meetings, the siblings had their meetings, the “boys” had their meetings, and the parents (and other interested adults) had their meetings. The sessions were excellent. I've been learning about BTHS for a very long time and like every other family member, I am ever eager to keep learning—and I was not disappointed. Thanks to one of our Barth dad's great suggestions, we started each session in small groups and talked about what questions we had and what we didn't understand about the upcoming topic. This information was

shared with the speakers, and all our questions were addressed. This was very helpful, because it gave the meetings a more interactive feel—which was great.

Additionally, parents and anyone else who was not able to attend the meetings were able to log on to Web-EX and hear the speakers and learn with all the rest of us. What a great addition this was for everyone; knowing these family members were involved made the sessions better for all of us.

The BSF Conference is hands down the most important thing we can do every two years for everyone in the Barth community—it is truly life changing. The Conference is the best way to collaborate and share and learn from and with each other. Collectively, we can find the answers to this very difficult disorder—but we all need each other to make this happen. I am grateful for everyone who came and shared, as everything we learn about each boy or young man helps all of the others.

I asked my son John what I should say about the Conference for this newsletter. He looked at me and said, “Oh that's easy—all you have to write is that the Conference is a fun gathering of a special group of people because we all understand each other.” And that pretty much sums it up.



# A Chance Encounter Leads to Barth Syndrome Involvement

By Todd Cade, PT, PhD, Washington University School of Medicine, St. Louis, MO, USA



Like several of us who attended the recent Barth Syndrome Conference in Clearwater, I had never even heard of Barth syndrome just a few years back. I still may not have if it wasn't for a chance meeting with Barry Byrne, MD, PhD, Professor of Pediatric Cardiology and Molecular Genetics at the University of Florida. As it went, in 2006 a colleague at Washington University

School of Medicine in St. Louis, the institution where I am employed, invited Dr. Byrne to come to St. Louis and give a presentation on the effects of gene therapy on muscle metabolism during our weekly Division of Endocrinology, Metabolism & Lipid Research seminar. Previous to this invitation, I did not know of Dr. Byrne. The night before the seminar, Dr. Byrne, my colleague, another faculty member and I went out to dinner. We discussed the metabolic and exercise physiology research that we do on people infected with HIV at Washington University. The following day, Dr. Byrne presented a great lecture to our faculty and then left for home.

About 1-2 weeks later, Dr. Byrne called me and asked me if I would be interested in coming to Disney World in Orlando during an international Barth Syndrome conference to help him and Carolyn Spencer, MD, Assistant Professor of Cardiology at Boston Children's Hospital, with a metabolic exercise testing study that they were conducting in individuals with Barth syndrome. He briefly explained the pathology and clinical presentation of Barth syndrome and I was immediately interested as I previously worked with HIV+ adolescents and desired to perform more research with children and adolescents in general.

After furiously researching all available articles regarding Barth syndrome, I arrived in Orlando for the 2006 Barth Syndrome Conference, fully expecting to be intrigued with the pathology of Barth syndrome on a scientific level but not expecting the extent that the boys would tug at my heart. To say the conference in Orlando was a wonderful experience for me would be an understatement. From working with the boys and young men, to meeting the families, scientists and physicians and watching the space shuttle take off from the pool, the experience had me hooked.

In the following two years between the conference in Orlando and this year's Conference in Clearwater, I kept in close contact with Dr. Spencer and Dr. Byrne regarding improving the current metabolic exercise study and developing new research ideas in Barth syndrome, particularly the idea of using the established research methodology employed in our HIV+ subjects here at Washington University and applying it to Barth syndrome. At this year's Conference, I was fortunate to be asked by Matt Toth, PhD, Scientific Director of the Barth Syndrome Foundation, to present to the scientists and physicians research techniques that I think may be able to tell us more about nutrient (sugar, fat and protein) metabolism in individuals with Barth syndrome. Currently, Dr. Spencer and I are developing a study that incorporates techniques that aim to examine the role of nutrient metabolism in skeletal muscle atrophy and heart function abnormalities in Barth syndrome. In short, we hope to examine how those with Barth syndrome metabolize nutrients and see if nutrient metabolism is dysregulated. If we find that it is, we want to learn if it contributes to skeletal muscle wasting and cardiomyopathy. It now seems that nutrient metabolism is important in these individuals, since the metabolic exercise testing study led by Dr. Spencer and conducted during this year's Conference found that subjects with Barth syndrome had severely impaired energy production and skeletal muscle oxygen utilization when compared to healthy control subjects. In other words, the ability of the muscles to extract and use oxygen for energy production during exercise and activity was impaired in the Barth individuals. These data not only indicate that nutrient metabolism may be dysregulated in these individuals, but they also suggest a mechanism for fatigue and activity intolerance in Barth syndrome.

During this year's Conference in Clearwater, I was fortunate to also give a presentation to the families, along with Randy Bryant, MD, Associate Professor of Pediatrics at the University of Florida, Jacksonville, on exercise recommendations for Barth syndrome. Having training as a physical therapist and in exercise physiology, I have experience with exercise in many different populations. The problem is that there is not much known regarding exercise in Barth syndrome. Therefore there is a pressing need for research in this area.

In summary, a chance encounter with a great scientist and physician allowed me to enter the world of Barth syndrome. I am grateful for that encounter and the invitation to work with the wonderful group of scientists, physicians, families and affected individuals involved in this intriguing and often heartbreaking condition. I hope to continue working with all involved until this syndrome is adequately treated or cured.



# An Apple a Day ...

## Making Strides Toward a Nutrition Prescription for Barth Syndrome

By Rhonda Avery, RD, LD/N, CDE, Watson Clinic, Lakeland, FL, USA



In 2006, I was introduced to Barth syndrome (BTHS) by Linda Croxton, a friend and colleague, and aunt of a young man with BTHS. She invited me to help her with nutritional issues related to BTHS at the Foundation's 2006 conference. The 2006 and 2008 conferences far exceeded my expectations. This conference brilliantly combines the scientific

component with personal perspectives. It allows families and health professionals to learn about all aspects of BTHS and become better advocates for their children and our patients. I left feeling grateful for the opportunity to meet and learn from such a wonderful group of boys, families and scientists. I left feeling inspired to find answers to new questions.

At the 2008 Conference, with guidance from Dr. Richard Kelley, Division of Metabolism, Johns Hopkins University, we focused on collecting data that would further enhance our understanding of metabolism in BTHS. We tested basal metabolic rates on the boys over 16, obtained triceps skinfold measurements, body fat percentages and looked for any visual indications of nutritional deficiency through hair, skin and nails. We also looked at a 24-hour diet recall and discussed food preferences.

### So What Did We Learn?

It appears that most of the boys are taking in adequate calories and protein. Measured resting metabolic rates correlated closely with the standards used to calculate normal resting metabolic rates. In those who have returned a 3-day diet history, the calorie intake has correlated with these calculations as well. Tricep skinfold thickness measurements are used to monitor changes in body fat and provide an estimate of energy (fat) storage. All of the boys were greater than the 50th percentile triceps skinfold for age, indicating adequate energy (fat) storage.

Based on diet recall and food preferences, there are vitamins, minerals and phytonutrients that are likely lacking in most of the boys' diets resulting from low intakes of vegetables, fruits, whole grains, monounsaturated (good fats) and omega-3 fats. Those taking a daily multivitamin and mineral supplement met their daily vitamin and mineral needs but were still lacking phytonutrients and "good" fats. Specific food preferences and food issues presented a barrier to increasing the variety of foods eaten by the boys. The severity of these issues differed among the boys. We did not look at the impact of cultural differences, medications and illness on food intake or food preferences.

What we know about nutrition and BTHS is growing but we still do not know what will be the best nutrition prescription. Dr. Kelley is currently looking at the benefits of specific nutrients in improving health and enhancing growth in boys with BTHS. To fully reap the benefits of these supplemented nutrients, we must also look to improve the overall quality of each individual diet as willing and able. The following tips may be helpful in accomplishing this.

### Food Issues

Food issues commonly discussed at the Conference included aversions to the sight, smell or texture of certain foods. For aversions based on sight, it is sometimes helpful to become familiar with the food. Simply placing the new food on the table can be beneficial. As the food becomes more familiar, the child is more likely to touch it or play with the food. Studies show it may take 15 or more exposures to the new food before they are receptive to trying it. Aversions to the taste and smell of foods are handled in a similar way. Add familiar flavors to the new food. For example, vegetables topped with cheese and hot sauce become more familiar and are less likely to be rejected. If these aversions are significantly affecting the ability to increase or maintain food intake, it is best to work with a speech or occupational therapist.

### Eating More "Good" Fats

Omega-3 fats are important for brain function and normal growth and development. They have received a great deal of attention lately secondary to their potent anti-inflammatory benefit which may be helpful in reducing risk factors for certain chronic diseases. Good food sources of these fats include fish, nuts, nut oils, walnuts, canola oil and flaxseed. Monounsaturated fats are another type of fat that offer health benefits. The best sources of monounsaturated fats include nuts, avocados, olives, natural peanut butter (the one with oil on top), olive, canola and peanut oil. Reducing saturated fats from high fat dairy, high fat meats, and "junk" food with these good fats helps to decrease inflammatory processes and improves overall health. Try to add some of these good fats every day.

### Phytonutrient?

A phytonutrient is a natural bioactive compound found in plant foods that works with nutrients found in fruits, vegetables and nuts to protect against disease. Many of the bright colors in fruits and vegetables come from phytonutrients. Lycopene and Lutein are examples of phytonutrients. Choose a variety of fruits, vegetables, nuts, whole grains and beans to reap the benefits of these potent nutrients. Look for cookbooks like *Deceptively Delicious* that have creative ways to "disguise" vegetables in favorite foods.





# SAVE the DATE

## Barth Syndrome 2010 International Scientific, Medical and Family Conference

July 26–July 31, 2010

Bay Point Marriott Golf Resort & Spa  
Panama City Beach, Florida

Our International Barth Syndrome Conference, held every two years, is really two simultaneous meetings. One meeting brings together doctors and scientists involved in the many aspects of the disorder to discuss the latest underlying scientific developments and clinical insights. It is a unique collaboration that accelerates advances in understanding and treatment. The other is a family meeting in which the latest information is discussed with families. Free clinics are also held enabling families to consult with medical experts from around the world. In addition, the clinics offer families the opportunity to provide important clinical data and biological samples to the Barth Syndrome Medical Database and Biorepository. Don't forget to bookmark [www.barthsyndrome.org](http://www.barthsyndrome.org) for more information as it becomes available.



Mark your  
calendars *NOW!*

See you there!



## Raising Awareness of Barth Syndrome

In October, Will, one of our adult young men, gave a presentation to the second-year genetic counseling graduate students at Sarah Lawrence College in their Biochemical Genetics course. He did a really great job educating these students about Barth syndrome!

# An Extraordinary Community with a Profound Sense of Urgency

By Linda Stundis, Executive Director, Barth Syndrome Foundation



Photo by Amanda Clark

When I was offered the position of Executive Director, I said, “This is the most exciting position I have ever held.” The opportunity to work on behalf of vulnerable children, to help advance the science and medicine of Barth syndrome, and to work with extraordinary families, was, for me, the opportunity of a lifetime. Three months

later, I know in my heart that it is the most challenging but the most important position I have ever held.

I am privileged to work with and for all of you—families, volunteers, physicians, scientists, donors and supporters—on behalf of the boys and men around the globe who have been diagnosed with Barth syndrome or who are awaiting a Barth diagnosis. I am grateful to be part of your extraordinary community—a community that is successfully challenging the limits of science and medicine to date, and a community which supports one another with a compassion and commitment I have not seen in my twenty years in the non-profit world.

The urgency of the BSF mission forced itself upon me during my first week on the job—when I started seeing the daily e-mails depicting the hope and despair of Casie and Scott Oldewage as their five and a half year old son, Christian was desperately fighting for his life...

The following week, at the 2008 International Conference, I was warmly embraced and welcomed, but the sense of urgency was underscored as I met your boys and young men...

And then, on August 17<sup>th</sup>, Casie and Scott lost little Christian... The outpouring of community support from around the world, which had been with the Oldewage family throughout their devastating journey, was once again immediate and deeply heartfelt.

For me, the Barth Syndrome Foundation represents this juxtaposition between an extraordinary community and a profound sense of urgency.

\*\*\*\*\*

As families, you are extraordinary because you live in the tension between hope and despair, yet hope prevails. You are extraordinary because you instill strength and a generosity of spirit in your children despite the daunting burdens of Barth syndrome. As scientists and physicians, you are extraordinary—because you refuse to give up on a rare, life threatening disease—you are doing what you can to advance the cause, to help push back the boundaries of science and medicine. As donors, you are extraordinary because you make possible the scientific and medical research, and you provide the funding needed to support the families, raise public awareness, and expand our programs.

As parents, you know that no one can fight this dreadful disease alone. Well, as the new Executive Director, I can help lead BSF to “the next level,” but I can’t do it alone either. The BSF community—staff, families, volunteers, physicians, scientists, donors, and supporters—we are all needed to help take our organization to new levels of public awareness, to the increased diagnosis of boys, to more effective and efficient communication across our virtual world, to expanded programs and services, and to increased levels of funding to drive the science and medicine to discover treatment protocols and ultimately a cure. The challenges are daunting—this must be a team effort, with each member of our community doing what you can, giving what you have to give. Your efforts are greatly appreciated. And if you are doing all that you can do, then your contributions are just as important as the efforts of any one of us.

Helping to save the lives of children, helping to improve the quality of life for children—it is the noblest of causes and among the most urgent—when the children are our children, the urgency is profound.

One of my favorite poets is Jorge Luis Borges. In one of his poems he writes these lines:

***In a... single day are all the days of time...  
Between dark and dawn lies the history of the world.  
Grant me... the courage...  
to ascend to the summit of this day.***

With courage and boldness, and most importantly, in community, we must ascend to the summit of each and every day, doing all that we can to advance life-saving treatments for all affected by Barth syndrome.



# It Was the Best of Times, It Was the Worst of Times...

By Stephen McCurdy, Chairman, Barth Syndrome Foundation

Let's face it. It's tough not to get a little bit depressed about the economic news of late. You don't have to be an economist, investment banker or any kind of financial guru to be able to read the headlines and appreciate the stress that is being felt around the world today. Each of us is trying to insulate ourselves from the economic storm by spending less and moving whatever investments we have to cash. Tight credit and de-investment cause unemployment to increase, and the downward spiral continues. No one can see a hint of optimism until these problems work their way through the system in 2010 at the earliest.

I have only written a paragraph and I bet that most of you have already moved on in search of a more uplifting article! Well, for those of you who are still reading, here is your reward—the Barth Syndrome Foundation continues to shine brightly and to move forward with confidence in its mission, its programs, its leadership and its financial health. Just consider the articles contained in this newsletter—the most successful Barth Syndrome Conference ever; the arrival of a new Executive Director with passion, experience and vision; a successful and growing research program which is helping to create a high degree of collaboration and trust among a talented and diverse group of scientists who continue to make new discoveries about Barth syndrome every day; increasing awareness; new families and volunteers getting actively involved in BSF and all of our affiliates. Everywhere we look, we are making great progress. Everyone involved is taking satisfaction in their work and contribution and has real cause for optimism.

Quite a contrast to the growing darkness and gloom that surrounds us, don't you think? So let me reassure you of two simple things: First, BSF has a strong balance sheet with reserves of over \$2 Million invested in government guaranteed CD's. Our past success in fund raising and our conservative investment policies have given us a solid financial cushion to carry us through tumultuous times. Second, ours is a strong, vibrant and loyal community. Our motto is simple and straightforward—We Will Never, Ever Give Up! As families, volunteers and friends, we have too much at stake in our sons with Barth syndrome, our daughters who may be carriers and future generations. And our donors continue to be inspired by a small but dedicated group, determined to solve this problem before it is passed to another generation. The economy may falter, and donations may be smaller, but we have faith in our friends and families that they will continue to stand side by side with us for the long run.

There is nothing so powerful as a shared vision, nor as underestimated as the fierce determination of a community fighting for our children. This is the simple cement that binds us together and that will continue to provide the support that is needed through good times and bad, until that vision is realized.

The families, the fund raisers and the donors reflected below and in our Power of Kindness pages are an important part of our community, and we owe you all our eternal thanks for your continuing support.

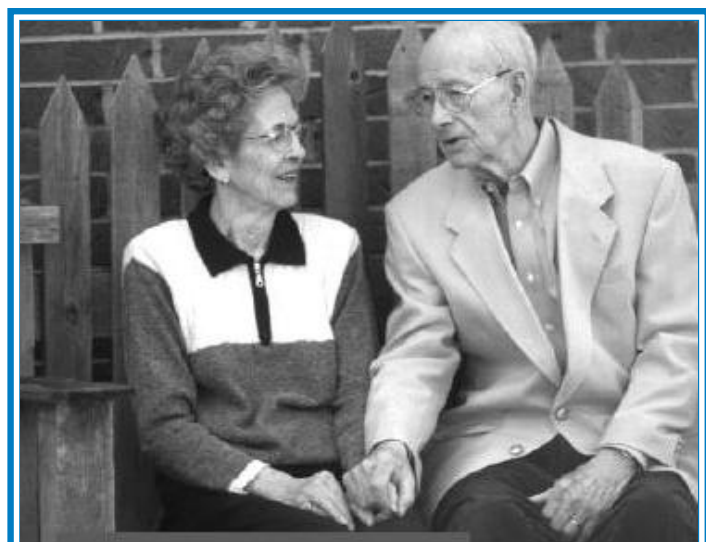
## Mrs. Annenberg's Generosity

Mrs. Leonore Annenberg has been a loyal and most generous supporter since BSF was founded, and our Science and Medicine program owes its start to her faith in us. Her most recent gift, in honor of Kevin, one of our young men, and all others with Barth syndrome, was announced at the BSF Conference in July and will help to sustain BSF's critically important research programs. A wise mentor of mine once said, "If you are going to be there for somebody, be there for them early when it really counts!" Mrs. Annenberg was there for us early, and she is still there for us today.

## The Paula and Woody Varner Fund

This fund was named in honor of Sue and John Wilkins' parents and grandparents, respectively, and who provided the first seed donation to get BSF started. Sue and her family continue to solicit their friends and the fund continues to grow. At the Barth Syndrome Conference in July, John Wilkins gave out the first Varner Award for Pioneers in Science and Medicine to Dr. Peter Barth and Dr. Richard Kelley. Both the crystal bowl and the honorarium given to these pioneers, as well as several directed research awards, have been funded by the Varner Fund.

*(Cont'd on page 12)*



*The late Paula and Woody Varner of Lincoln, NE, in whose honor the BSF's Paula and Woody Varner Science & Medicine Fund was established.*



# It Was the Best of Times, It Was the Worst of Times...



## Our Barth Triathletes!

Gary Rodbell is back once again with 'Team Will' to support BSF with newly designed, eye-catching riding gear apparel!



Jess proudly completes the Big House Big Heart 10K run in support of BSF!

## Our Barth Syndrome Triathletes

Once again, Coach Gary Rodbell and his growing band of triathletes have combined their extraordinary athletic and fund raising skills to benefit BSF under the name "Team Will." Chef Matt Karp raced in the Wisconsin Iron Man; Gary, Angelo Mancino, Laura Azar, Paul Epstein, Jeff Knopping, Heather Segal and Jack Steinberg raced in the half Ironman (The Timberman) in New Hampshire. On September 21, 2008 all of the Timberman triathletes plus, Matt, Jaime Jofre, Stephen Tunguz, Francois Odouard, Joanne Jensen and Kayleigh Monetti—13 athletes in all—raced for the Barth Syndrome Foundation in the Westchester Jarden Olympic-length Triathlon. Each of our triathletes had sent electronic or written solicitations for BSF and received more than 100 donations in return.

## Jessica's Big House Big Heart Run

The Wilkins family have all been strong, loyal supporters of BSF and John's sister, Jessica Wiederspan, is no exception. She took advantage of a 10K run at the University of Michigan called "Big House Big Heart" to raise money from friends and family to support BSF. Each contributor received a flyer on Barth syndrome so once again, a fund raising activity works to raise awareness as well as to fund needed programs.



(L-R) Jack and his friends support BSF by bowling in the 5th Annual Barth Bowling Fundraiser in Warwick, NY.

## The Bowl-a-thon is Back!

Liz and John Higgins and their many friends, including Lynda Sedefian and the Dunn family who drove down to Warwick, NY for the event, filled over 20 lanes with happy bowler/donors, proving once again how much fun fund raising can be! The fifth annual bowling fundraiser not only raised money for BSF, it also helped raise awareness of Barth syndrome.

(Cont'd on page 13)



*(L-R) Randy Buddemeyer, Tim Rivers and Randy's son, age 19, at the CB Richard Ellis Golf Tournament.*

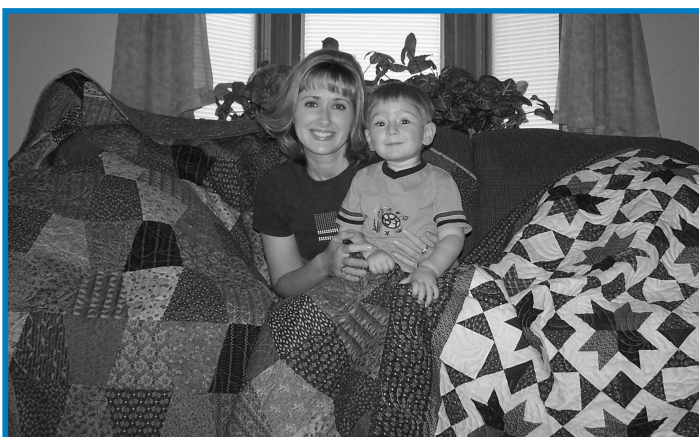
## The CB Richard Ellis Golf Tournament

On May 19<sup>th</sup> over 160 golfers helped make the event a success by gathering to enjoy an afternoon of golf, contests, silent auctions and an exciting raffle—all made possible by generous donations from a variety of Tampa Bay area companies, as well as participants and sponsors throughout the east coast.

Event sponsors, Allied Barton, Ed Taylor Construction, Potomac Service Link, Otis Elevators and CB Richard Ellis' Asset Services Group raised \$140,000 for BSF and the Tampa chapter for Juvenile Diabetes Research Foundation (JDRF). The event raised enough money to donate \$65,000 to each charity. "Three years ago Tim Rivers and I made the decision to host this event to bring our community together to help support the JDRF and BSF and their missions to save the lives of young children everywhere. Over the last three years, we have raised in excess of \$290,000 for these very worthy

causes. We cannot thank everyone enough," said Randy Buddemeyer, Managing Director—CB Richard Ellis.

Randy's son, who was diagnosed with Barth syndrome at the age of 14, expressed, "I thank everyone greatly for their participation in the event and contributions to BSF. I know that the money donated will greatly aid in our search for a cure."



*Tracy Brody and her 4 year old Barth son proudly display the beautiful quilts that were raffled off at our Conference.*

## Quilt Raffle a Major Success

For months before and during the Conference, Tracy Brody worked to create her unique and beautiful quilts and to sell raffle tickets to hopeful quilt winners! Her handiwork and raffle was featured in local newspapers in Iowa, on-line to the BSF community and throughout the Conference, and she exceeded all expectations in terms of fund raising. The ultimate winners of the Quilt Raffle were Maggie Hecht of Larchwood, IA and NorAnne Brost of Nekoosa, WI who were thrilled to own such beautiful quilts and have a new appreciation of Tracy, Barth syndrome and the BSF cause.

## Conference Sponsorship on the Rise

The Barth Syndrome Conference held in Clearwater, FL in July attracted a record number of sponsors including The Barth Syndrome Foundation of Canada, The United Space Alliance Employees' One Fund, Bright Circle Inc., Lucas Productions, Allen and Rosa Mann, and the McCurdy, Sernel and Wilkins

Families. Amanda Clark and the Pinellas County EMS contributed their substantial talents to make us all look good and feel safe. Also, an incredible array of physicians and medical personnel donated their time and expertise during two long days of clinics to assess and advise our children and families, and gather invaluable data and samples for the Barth Syndrome Medical Database and Biorepository.

## Leaving a Legacy

Many families are suggesting that in memory of a loved one, or in celebration of an important event, those who wish to commemorate the individual or event might make a donation to BSF instead of sending flowers or a gift. BSF has received donations in honor of bar mitzvahs, weddings, anniversaries, birthdays—all celebrating major events in the life of someone important to the donor. In many cases, these donations were suggested by the parents or the celebrant themselves. Gifts have been given in honor of several of our boys and young men (Bly, William, Jack, Kevin, Will, Ryan) and parents (Ed Floyd and Sue Wilkins), Adam Halper and the members of *Team Will*.

Recently we have also received donations in memory of members of our own Barth community, gifts that come to BSF with a special sadness and appreciation. In 2007 to the present, these have included gifts in memory of Irene Mary Kugelmann, Steve Kugelmann's Mom; Paula Varner, Sue and John Wilkins' Mom and Grandmother; Robert Lochner, Lynda Sedefian's brother; Christian Oldewage, Casie and Scott's little boy; Tony Satula, Doris Dugan and David Bruyette. These gifts are a wonderful way to leave a legacy in honor of a family member or friend by supporting a cause that is/was important to them. We very much appreciate and respect these gifts and are honored to receive them.





# In Memory of Christian

By Scott and Casie Oldewage, Utah, USA



**O**n August 17, 2008 our little angel, Christian Michael Oldewage, closed his piercingly deep, beautiful blue eyes, stretched his mighty wings, and took flight from this earth. He will forever be missed by his loving mother, father, sister and brother and all those whose lives he touched along his path of just five and a half short years.

And boy did he touch lives. We wish you all could have seen the number of people that honored him at his service. For such a little man of so few words who lived in a sheltered bubble most of his life – he had a profound effect on everyone he came in contact with. Nowhere was the effect felt more profoundly than within the confines of his own family. He taught us so much, pulled us so close, and became the nucleus of our family. His sister Alexis said it best when she said, “We are all the petals of a flower and Christian is the center of the flower holding us all together.”

Christian was so valiant. Never did he ever complain of his affliction. Never did he give up on anything just because he was smaller, weaker, slower or a little more fatigued. He would just reach inside that gigantic heart of his and love everything about life.

Christian was always so easy to please. Do you know that all he asked for last Christmas was a Superman ball? Well, that was until he saw the 3’ tall Robosapien interactive robot. But that aside, Christian was always so content with the simplest of things.

Saturdays. How he loved Saturdays. Every Friday night, before tucking Christian into bed we would ask, “Christian, what day is today?” and he would respond, “Friday” and next we would

ask, “What day is tomorrow?” and he would reply, “Saturday” and we would then ask, “What happens on Saturday?” and with glee in his voice he would joyfully shout out, “Daddy doesn’t have to go to work tomorrow - yeahhhhhh!”

Nothing made Christian more content than being in his mother’s arms. He loved his mother so much. In fact, he loved her more than anything in this world. It was this love and bond that gave her the intuition and foresight to give Christian the care he needed as well as give him the strength to battle through obstacle after obstacle.

Christian was a Superhero to us all. Whether it be Superman or Ironman he magnified the inherent qualities that make Superheroes super. For such a little man he often seemed so much larger than life. He taught us all to be stronger, better, more caring people.

The last 3 months were very difficult months for Christian. He endured more than most anyone could bear or should ever have to bear– and he bore it all with courage. He was never afraid – even when we as parents were terrified. He gave us all hope. He gave us courage. He inspired the entire medical staff to strive harder, search deeper, and invest more. He truly was and forever will be an inspiration to us all.

Most of all, Christian was a fighter. He never gave up. He never, never quit. But like so many past battles fought, even the hero sometimes faces insurmountable odds and for Christian, Barth syndrome was that insurmountable odd.

But like any Superhero would, Christian did the noble thing. He donated his heart and his blood to you all, hoping that it will help assist our other little heroes. That one day, should they face his same battle; they will be empowered with the research and knowledge necessary to overcome this wicked disease. And as his just reward...his heart now beats strong, he feels no pain and most importantly, our beautiful angel is no longer affected by Barth syndrome.

We love you Christian. May the Lord hold you tightly until we are with you again.

As a family, we would also like to express our deepest gratitude to Dr. Kelley. He was always willing and available at any hour ready to assist in whatever way possible to make Christian well. Thank you Shelley Bowen for all that you have done and continue to do. Thank you to the medical professionals involved in his care. Thank you to those special people who have made considerable donations to BSF in honor of Christian. And thank you to you all for your thoughts, prayers, kind words and support as we continue to travel this very difficult road.





# The Long Journey Through Diagnosis

By Shelley Bowen, Family Services, Barth Syndrome Foundation

Most of our families have experienced that long and lonely journey before we learned that Barth syndrome (BTHS) was the disease that plagued our sons. Many of the boys went through painful biopsies, tests and systematically went from one potential disease to the next. All the while, we just wanted to know the name of the nemesis that was attacking our beloved child.

According to the National Organization of Rare Disorders (NORD) it takes an average of five to seven years for a rare disease to be diagnosed. Now that our children have a diagnosis, we know all too well how beneficial that can be. We can be informed about what is going on in our son's body and be more informed about potential risk factors and contraindicated treatments.

Still far too many children are out there who have BTHS and are in peril without a diagnosis. In many ways, these are the most difficult of days, months and sometimes years. There is no support group from which one can obtain assistance. There are no peer families from which someone can learn how to advocate for their child. You are just out there, in limbo, not knowing if whatever it is will place your child in harm's way.

Over the years, BSF's Family Services team has supported many families through this difficult phase. We have committed our support to them to obtain a diagnosis, and if that diagnosis is not BTHS we have been there with them until a diagnosis can be found. It is not always as simple as some may think to obtain a diagnosis. We know this because we have lived it. These are the families you don't meet until a confirmed diagnosis is made. We cannot introduce them to the group because we don't want them to find a sense of place only to be told that this is not the place for them. So, behind the scenes we work with these families going through these difficult days and lend our support through this process.

We felt compelled to share a story of one such family being supported through this heartbreaking journey. Today, they still don't have a confirmed diagnosis, but we are committed to help them through it because we too were once in their same position.

## A Family's Mystery Diagnosis

By Deb Sutton

"Ask and it shall be given you; seek and ye shall find; knock and the door shall be opened." Knowledge—it helps us find comfort and gives us direction for the future. But where do you ask, seek, and knock when the unthinkable has just become your reality?



(L-R) Jesse, Nathan and Abbe Sutton. (Photograph taken March 22, 2008).

In the past six months, two phone calls have utterly transformed my life. The first call came around 6 pm on April 3, 2008. I had been trying to call my 20 year old son, Nathan, for six hours. He was coming home for a visit and I was making the semester's last "Costco run." I needed to determine how many frozen cheeseburgers he would need to make it through finals. With each passing hour, my irritation and concern grew. Finally, my cell rang. It was Lee University; right place, wrong voice. "Dr. Who? Sorry, you called to tell me what? No!"

Sure, ever since Nathan had had a stroke at the age of two years, he had had seizures. But he had always fully recovered, he'd always pulled through. In 2006, he even had a seizure driving in Atlanta traffic. However, minutes before it happened, traffic had miraculously slowed and he was able to put his car in park. Eighteen years of seizures and he had always won.

This had to be a mistake. Our beautiful, overcoming Nathan couldn't be gone! How could a parent receive this unthinkable news and not be there? We had to go to him. Then the next shock came when we were told we could not see our son for a day or two and even more difficult was to hear him referenced as "the body." How could the state mandate that our son have an autopsy? We were furious; we didn't want an autopsy. We just wanted our son. At that time we had no appreciation of the impact the autopsy results would have in our lives.

The second life-changing call came about 12 weeks later from the Bradley County Coroner's office. The long-awaited autopsy results were back. The Coroner discovered that Nathan had dilated cardiomyopathy with left ventricular non-compaction (LVNC). He said this rare, congenital heart disease is sometimes associated with Barth syndrome. I couldn't grasp this new piece of information. After all these years of CT scans, EEG's and cranial MRI's, how could we have missed something like this? How could someone as seemingly healthy and remarkably athletic as Nathan have a heart disease?

(Cont'd on page 16)

# The Long Journey Through Diagnosis

(Cont'd from page 15)

I immediately searched the Internet for any information I could find. There wasn't much, but I did find The Barth Syndrome Foundation's website. I sent a brief e-mail to BSF explaining our situation and asking for information. I expected to eventually receive a return e-mail with some "cold" medical facts. I didn't anticipate a warm, caring, personal phone call less than one day after sending the message to BSF. After receiving that call, Shelley Bowen became a major part of my life. Shelley didn't just call me with information; she wanted to know my son and my family. She entered into our pain and became the place where I could not only ask, seek, and knock, but where I could cry without restraint, and find hope for tomorrow. That two hour call was the first of many.

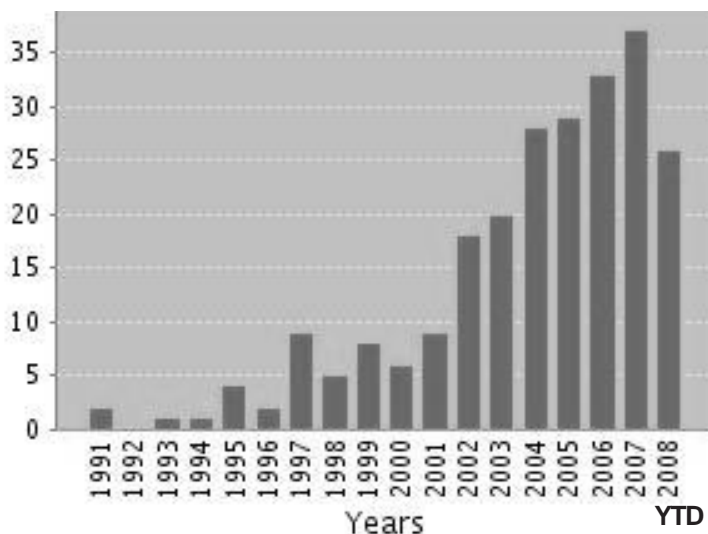
Nathan's case is not "typical" of Barth syndrome, and we are still in the midst of confirming the diagnosis. The only DNA that exists for Nathan is contained in a blood spot card. We cannot squander this precious sample of DNA. Our quest continues to uncover the cause of his LVNC. However, we are not alone in this journey. During that first phone call, Shelley promised that she would stand with us and help us find the information we needed. She contacted a geneticist in Atlanta and sent me a number of articles. With this new information, the puzzle that was Nathan's life started coming together. After 18 years of numerous blood tests and brain scans, the neurologist had been unable to determine why Nathan had had a stroke or why he had seizures. This past spring, he was continuously exhausted and just never seemed to feel well. His father and I constantly nagged him to take better care of himself and get consistent sleep. We had no idea his heart was failing. I wish we could go back now and tell him how proud we are of him. I can't imagine how hard he must have pushed just to make it through every day. But, then, that's what these boys do.

Only through our faith have we found comfort in knowing that our Nathan is no longer suffering. Us? We're still on this journey of grief and discovery. However, because of the love of Shelley and this Foundation, we know where to turn and find comfort in the knowledge that we are not alone in this journey. Thank you!



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

Articles Published in Each Year



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

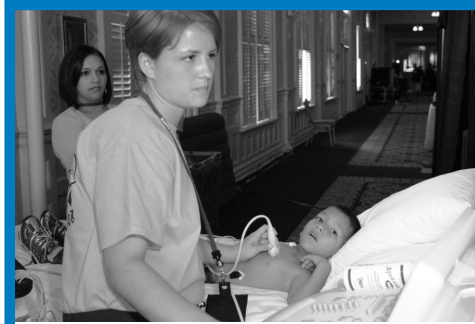
It is clear that the awareness of Barth syndrome is growing each year.

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

# Awareness of Barth Syndrome is Growing Exponentially

There has been a significant increase in Barth syndrome related peer-reviewed journal articles published. To date, there have been 23 articles published with the support of BSF and/or BSF affiliate funding.\* Listed below are the articles added to BSF's library since June 2008:

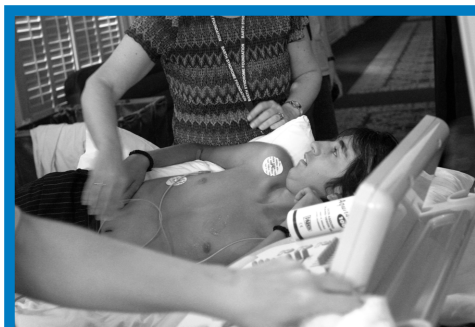
- Huang SC, Wu ET, Chiu SN, Hwu WL, Wu MH, Wang SS. **Mitral annuloplasty in an infant with Barth syndrome and severe mitral insufficiency: first case report and determination of annular diameter.** J Thorac Cardiovasc Surg. 2008 Oct;136(4):1095-7.
- Tikhomirov E, Averyanova N, Basargina E, Degtyareva T. **Gene symbol: TAZ. Disease: Barth syndrome.** Hum Genet. 2008 Oct;124(3):315-6.
- Hauff K, Linda D, Hatch GM. **On the mechanism of the elevation in cardiolipin during Hela cell entry into the S phase of the human cell cycle.** Biochem J. 2008 Sep 23. [Epub ahead of print]
- Kaewsuya P, Miller JD, Danielson ND, Sanjeevi J, James PF. **Comparison of N-alkyl acridine orange dyes as fluorescence probes for the determination of cardiolipin.** Anal Chim Acta. 2008 Sep 26;626(2):111-8. Epub 2008 Aug 15.
- Chen S, Tarsio M, Kane PM, Greenberg ML. **Cardiolipin Mediates Cross-Talk between Mitochondria and the Vacuole.** Mol Biol Cell. 2008 Sep 17. [Epub ahead of print]\*
- Claypool SM, Boontheung P, McCaffery JM, Loo JA, Koehler CM. **The Cardiolipin Transacylase, Tafazzin, Associates with Two Distinct Respiratory Components Providing Insight into Barth Syndrome.** Mol Biol Cell. 2008 Sep 17. [Epub ahead of print]
- McCanta AC, Chang AC, Weiner K. **Cardiomyopathy in a child with neutropenia and motor delay.** Curr Opin Pediatr. 2008 Oct;20(5):605-7.
- Claypool SM, Oktay Y, Boontheung P, Loo JA, Koehler CM. **Cardiolipin defines the interactome of the major ADP/ATP carrier protein of the mitochondrial inner membrane.** J Cell Biol. 2008 Sep 8;182(5):937-50.



*Michael, Age 6  
2008 Barth Cardiology Clinic*



*Ben, Age 11  
2008 Barth Cardiology Clinic*



*Robert, Age 18  
2008 Barth Cardiology Clinic*

*Our Barth guys participate in the Cardiology Clinic at our 2008 International Barth Syndrome Conference.*

- Towbin JA. **Molecular mechanisms of pediatric cardiomyopathies and new targeted therapies.** Progress in Pediatric Cardiology, Volume 25, Issue 1, April 2008, Pages 3-21.
- Menon SC, Olson TM, Michels VV. **Genetics of familial dilated cardiomyopathy.** Progress in Pediatric Cardiology Volume 25, Issue 1, April 2008, Pages 57-67.
- Wilkinson JD, Sleeper LA, Alvarez JA, Bublik N, Lipshultz SE and for the Pediatric Cardiomyopathy Study Group. **The Pediatric Cardiomyopathy Registry: 1995-2007.** Progress in Pediatric Cardiology Volume 25, Issue 1, April 2008, Pages 31-36.
- Bublik N, Alvarez JA, Lipshultz SE. **Pediatric cardiomyopathy as a chronic disease: A perspective on comprehensive care programs.** Progress in Pediatric Cardiology, Volume 25, Issue 1, April 2008, Pages 103-111.
- Joshi AS, Zhou J, Gohil VM, Chen S, Greenberg ML. **Cellular functions of cardiolipin in yeast.** Biochim Biophys Acta. 2008 Aug 7. [Epub ahead of print].\*
- Andrews RE, Fenton MJ, Ridout DA, Burch M; British Congenital Cardiac Association. **New-onset heart failure due to heart muscle disease in childhood: a prospective study in the United Kingdom and Ireland.** Circulation. 2008 Jan 1;117(1):79-84. Epub 2007 Dec 17. Comment in: Circulation. 2008 Jan 1;117(1):11-2.



# NIH Research Initiatives Seeking Applications

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

## [Roadmap Transformative R01 Program \(R01\) RFA-RM-08-029](#)

**Purpose:** To provide support for individual scientists or collaborative investigative teams who propose transformative approaches to major contemporary challenges. To be considered transformative, projects must have the potential to create or overturn fundamental scientific paradigms through the use of new and novel approaches. Successful projects will be expected to have a major impact in a broad area of biomedical or behavioral research. Projects will reflect ideas substantially different from mainstream concepts being pursued in the investigator's laboratory or elsewhere.

## [The Role of Cardiomyocyte Mitochondria in Heart Disease: An Integrated Approach \(R01\) RFA-HL-10-002](#)

**Purpose:** To develop an integrated understanding of cardiomyocyte mitochondria and its contributions to myocardial adaptations and heart disease progression by combining functional data with information derived from powerful new technologies.

## [Nutrition and Diet in the Causation, Prevention, and Management of Heart Failure \(R21\) PA-06-136](#)

**Purpose:** To encourage submission of investigator-initiated research applications on the role of nutrition and diet in the causation, prevention, and treatment of cardiomyopathies and heart failure. Basic, translational, and applied interdisciplinary research applications with rigorous hypothesis-testing study designs using animals or humans are of interest. The overall goal is to develop a satisfactory science base for preventive approaches in high-risk individuals and for rational nutritional management of patients in various stages of heart failure.

## [Development of Animal Models and Related Biological Materials for Research \(R21\) PA-07-336](#)

**Purpose:** To stimulate novel areas of investigation related to laboratory animal science and medicine and model systems that do not fall within the categorical interest of a single institute or center (IC) of NIH.

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

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

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

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

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

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

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

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

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

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

Please refer to [www.barthysyndrome.org](http://www.barthysyndrome.org) or the NIH website (<http://grants.nih.gov/grants/guide/index.html>) for more details about these and other funding opportunities.



# Why I think Barth Syndrome is Underdiagnosed

By Colin Steward, FRCP, FRCPCH, PhD, Royal Hospital for Children, Bristol, England



Colin Steward, FRCP, FRCPCH, PhD,  
Royal Hospital for Children, Bristol, England

The seeds of my belief that Barth syndrome is underdiagnosed go back a little over a decade to the detection of our first cases in Bristol. Ironically the story started with a boy who turned out NOT to have Barth syndrome, despite having 3-methylglutaconic aciduria, severe neutropaenia and myopathy. Trying to find his diagnosis, however, sparked a discussion with our Consultant Paediatric Biochemist in Bristol who pointed out that the Haematology team had already missed one case, in a boy who had required a cardiac transplant. Urgent discussions followed with our cardiologists, pathologists and intensivists, and within one year we had identified five affected boys from four unrelated families.

Things slowed down after that and since then we have only identified one new family in South West England and South Wales approximately every two years. This may not sound impressive, but only 6 million people live in our catchment area. Extrapolation of this incidence to the whole UK suggests that we would have almost 100 affected families nationally, not far off the total number of families diagnosed in the world to date!

So why do I think the disease is so seriously underdiagnosed? To answer that, I think that we first need to think about the nature of genetic disease. Some diseases are caused by only one or a very small range of mutations. Sickle cell anaemia for instance is a genetic anaemia caused by the same mutation in all patients, yet even here there can be enormous variation in how the disease shows itself. The same mutation can cause death due to acute pooling of blood in the spleen of a young baby or no problems throughout life so that the diagnosis may only be made as an incidental finding at post mortem. By contrast, Barth syndrome is a very complex disease with many different (so called “private”) specific mutations in the tafazzin (*TAZ*) gene and just a few hotspots (where the same mutation is found in multiple families). Furthermore, the proteins produced by reading the code of the *TAZ* gene also vary from organ to organ because the message read off the gene and sent to the protein factories is “spliced” differently—much like different news editors might produce a different version of the news from the same piece of film. This means that not only does the severity of the disease vary markedly from patient to patient but also the balance of how it affects the blood, heart, muscles or other tissues between individuals.

The practical consequences of this for making diagnoses are unfortunate. A cardiologist who is aware of Barth syndrome may well consider the disease if he or she finds neutropaenia in a blood count. But we now know (due to enormous input from all you boys and parents) that neutropaenia is only present intermittently in some boys and perhaps never in about one in ten affected boys. Therefore if neutropaenia is absent, the test for Barth syndrome will most likely not get done.

A new child presenting to a haematologist because of recurrent neutropaenia will be investigated for a myriad of diseases but almost certainly not for Barth syndrome. Poor growth in such a boy would probably be blamed on undiagnosed infections due to the neutropaenia. If we read the medical journals we are told that children with Barth syndrome are supposed to have cyclical neutropaenia (most don't) and compensatory monocytosis (rarely). So the test for Barth syndrome would not get done.

A baby presenting with hypoglycaemia and lactic acidosis might well be investigated for mitochondrial disease. If that child had Barth syndrome we know that a muscle biopsy might show abnormal respiratory enzyme abnormalities or abnormal looking mitochondria. This would clinch a diagnosis of mitochondrial disease in the eyes of many paediatricians. Yet in the UK no child with such a presentation, even if accompanied by weak muscles in the upper arms and legs, almost no child would get tested for Barth syndrome.

These comments are not based on hypothetical cases. Each is based around one or more real presentations in children known to me. And Barth syndrome does not even appear on the lists of potential diagnoses for proximal myopathy, feeding problems, failure to thrive, food fads or ventricular arrhythmia.

To make things worse, I am increasingly convinced that many foetuses with Barth syndrome are never live born or die very soon after birth from sepsis and heart failure. We now know for sure that children with Barth syndrome can be miscarried late in

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pregnancy or stillborn. For this knowledge, I am indebted to a number of mothers who have bravely shared their stories of tragic loss. Two of them lost five babies between them. We also have reason to believe, although there is as yet no definitive proof, that Barth syndrome may cause miscarriages much earlier in pregnancy, and we know for a fact that cardiomyopathy can be present as early as 18 weeks after conception.

By now, you are no doubt feeling upset at how ineffective our diagnostic procedures are, but I believe that the end of this rainbow is in sight. Until recently, we had to rely on measuring organic acids in urine and cardiolipin in blood or skin cells. But the level of the main organic acid, 3-methylglutaconic acid, is only slightly elevated compared to some diseases where the levels are so high that they can be used diagnostically—so many biochemists overlook the abnormality. We also found that cardiolipin levels could be normal in boys with typical Barth syndrome even when they had a proven gene mutation.

The answer to our prayers comes as a “gold standard” blood test developed at AMC in Amsterdam with the support of a BST/BSF research grant and published earlier this year. This test measures the ratio of a cardiolipin called monolysocardiolipin (MLCL) to cardiolipin, which has been found to be highly abnormal in all boys so far tested. It can be performed on many different tissues and even on a single blood spot on a filter paper (like the Guthrie spots taken from newborn babies) even where these have been stored for many years.

For years, the many boys whom we diagnosed in Bristol were thought by some to represent a “cluster”, a statistical quirk with little relevance to the rest of the world. Now, at last, we have a test which can be rolled out to look at much larger diagnostic groups: to groups of boys with cardiomyopathy, neutropaenia, hypoglycaemia, unclassified mitochondrial disease and to samples from miscarriages. At last we can begin to find out just how rare Barth syndrome really is.



## Barth Syndrome Trust ~ Something so Worthwhile

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



Photo by Amanda Clark

My husband quite enjoys the looming of a Barth Syndrome Journal deadline. The atmosphere crackles with anticipation, and we live in a Hogwarts-type home where wonderful dinners magically appear in our dining room. Even the house has been spring cleaned, even though it's taken me into winter to do it. Why the procrastination when it comes to reporting back?

Within the Barth Syndrome Trust (BST), the doing is the easy part—there is so much to do and all of it is important and worthwhile. To stop and take stock of what we've done is often more challenging, but it forces us to constantly check if we are making a difference and how we can improve.

This has been a busy and productive year, and it's been gratifying to see some major projects into completion. Reporting on achievements can be difficult because the effect of much of our most important daily work—raising awareness and helping families—is hidden. Our fight to get children diagnosed

and our support for parents who have seriously ill children cannot be measured or shown in a pie chart. But this is a very precious part of our mission.

We have been busy looking at different secondary school options for our ten year old son who has Barth syndrome. Being able to talk to other families has really helped me approach this issue with a lot more information in hand. It doesn't seem that long ago that we were looking at nursery schools, and now I have a fully-fledged adolescent in the house. Well, he tells me that at ten years old, he is practically a teenager and old enough to be responsible for his life (code for “Do as I please”). My younger son has taken up the recorder, and as I write this, the dulcet tones of “Jingle Bells” drift down the stairs and penetrate through my tightly-wedged ear plugs. As the end of the year and Christmas approach, this is a time to celebrate family and friendship and staying in together. Whilst our home may sometimes be more chaotic than we would prefer, we wouldn't change it for the world. Volunteering for BST certainly adds to the chaos, but being a small part of something so worthwhile brings rewards beyond imagination.

Happy holidays to you all and warmest wishes.

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## Bristol Clinic

Our Barth family numbers in the UK and Europe are increasing, and we are constantly trying to improve the services we provide. We're looking forward to our clinic and meeting in Bristol on **12–13<sup>th</sup> December 2008**. The clinic is very hands-on, organised by the families and conducted in a relaxed and informative atmosphere. It is truly "our" clinic and a vital resource for our community.

This year we will be doing our usual cardiac research clinic with Dr. Bev Tsai-Goodman and her team, followed by Question and Answer Time with Dr. Colin Steward and his colleagues. We will be submitting update forms and blood samples to the International Barth Syndrome Medical Database and Biorepository in order to advance research and to increase the numbers of participants. Nutrition will be another major focus this year with families being asked to complete food diaries. And lastly, we'll make sure we have fun and spend time together too, as this is always one of the most exciting parts of the meeting.

## New Projects



The poster features a photograph of a young boy on the left. The text on the right reads: **Barth syndrome**. Do you know of a boy with this genetic disorder? Main symptoms include all or some of the following: heart problems, recurrent infections, muscle weakness, fatigue, growth delay, feeding problems. New fast diagnostic test now available. **Barth Syndrome Trust**. Please contact us for information, services and support. Tel: 01794 518785. www.barthsyndrome.org.uk. Saving lives through education, advances in treatment and pursuit of a cure. Registered Charity Number: 1100935.

From the original design by Rob Ayton

## Awareness

We have been hard at work creating an eye catching poster which is being displayed in hospitals around the country. Volunteers are now translating the poster into various languages. Please contact us if you would like a few to display in your local hospitals.

## Science and Medicine

### Funding Research

To date, the Barth Syndrome Trust (BST) has part-funded the following Scientific and Medical Advisory Board-approved research grants. Our emphasis has been to contribute towards those projects taking place in the UK and Europe. Many thanks to all our families and friends whose fundraising efforts have made this possible.

- **Taco Kuijpers, MD, PhD, University of Amsterdam, The Netherlands**  
*Neutropaenia in Barth syndrome: new in vitro models to study BTHS neutrophils*
- **Willem Kulik, PhD, University of Amsterdam, The Netherlands**  
*Development of BTHS screening using bloodspots and HPLC tandem mass spectrometry*

- **Frédéric M. Vaz, PhD, University of Amsterdam, The Netherlands**

*Identification of the proteins interacting with tafazzin and resolution of the consequences of the deficiency of cardiolipin at the protein level*

We also provided funding for two key clinicians from the UK to attend the 2008 International Barth Syndrome Conference in Clearwater, Florida.

## BST Dates for your Diary

**12–13<sup>th</sup> December 2008**

Barth Clinic, Bristol

**31<sup>st</sup> January 2009**

BST Volunteer Workshop, Overton, UK

**26<sup>th</sup> April 2009**

European Family Gathering

Archeon Park, Alphen a/d Rijn

The Netherlands (*details to follow*)

## Family Services

Attending the International Conference, although highly beneficial, places financial pressures on families. This year the Trustees decided that BST should fund one family (chosen by draw) to attend. Our lucky winner of £2000 towards the cost was Marlène Carvalho from Portugal, and it was as exciting for all of us to meet her and her sons as it was for her to attend. Her story follows.

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## A Family's Experience of Attending the International Barth Syndrome Conference



Photo by Amanda Clark

### A Wonderful Gift

By Marlène Carvalho, Portugal

I am going to tell you a story, a true story. In 2000, I attended the first-ever Barth Syndrome Conference in Baltimore with my six year old son. It was a great financial strain but one that I believed was essential. Unfortunately, since then I haven't had the means to attend another conference and I missed these gatherings.

So when BST announced that they would donate 2500 Euros to one of the UK and European families to help finance their trip to the 2008 Conference in Florida, I entered the draw hoping to be the lucky one. I had never won anything before, but I believe there is always a first time for everything in life. And it's true. I WON! It was the most wonderful gift I could have received.

We had great difficulty trying to find specialist medical and travel insurance, but with Annick Manton's persistence (BST Family Services), we finally succeeded. Together with my 15 year old

son (who has Barth syndrome) and my 12 year old son, we were soon on a plane on the most important trip of our lives.

When we arrived in the States, we found another family, OUR family, with lots of love and friendship, sharing the same problems and the same joys. Despite our language differences, I felt that we were no longer alone and that the world was reaching out to us, bringing us information, new friends and a caring family. It is a pity that I do not speak English because it was difficult to communicate with other families and with the doctors. Fortunately, Annick and Michaela are fluent in French and so am I. They never left our sides and were both a constant source of support throughout the Conference.

I learnt a lot about my son's illness and benefited greatly from the experiences of the other families. I learnt to better understand my son and his daily struggles. Today, I am more equipped to help him and that is most gratifying. From the bottom of my heart, thank you Barth Syndrome Trust, Michaela and Annick. You are contributing to a better quality of life for my son and for that I will never be able to thank you enough. T H A N K Y O U.

### Other Family Services News

Many of our families have spoken of the bewildering time before and just after diagnosis when they were overwhelmed with information and fear. At our volunteer workshop, families explored ideas for a **New Family Brochure**. The resulting brochure is nearing completion and will be a friendly, low key introduction to BST and a signpost to finding the right path for newly-diagnosed families.

### Volunteer Meeting

After a successful meeting on 25<sup>th</sup> October, the Trustees joined volunteers from the Hampshire area for a meeting. Our Chair, Michaela Damin gave an update of news and challenging plans for the Barth Syndrome Trust (BST) which emphasised the need for fundraising.

And a very warm welcome to our new trustee, Gemma Wilks. Gemma, who is a Chartered Accountant, has already brought new ideas to the Trust and a fresh impetus to our fundraising. Thank you for giving us your time and expertise, Gemma.

### Other News

#### Credit Crunch

We are affiliated to the national charity "Contact a Family" whose recent survey has revealed that families with disabled children are under increasing pressure to survive in the worsening economic climate. Contact a Family will be urging the government to increase Disability Living Allowance, to extend Winter Fuel Allowance, increase and review Carer's Allowance and introduce further measures to support families. We will inform you of any change in benefits. BST has also produced a leaflet on all sources of benefits available to UK residents—please contact us if you would like a copy.

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# Barth Syndrome Trust ~ Something so Worthwhile

(Cont'd from page 22)

## Children's Heart Week 9–17 May 2009

The Barth Syndrome Trust (BST) is also affiliated to the Children's Heart Federation, and together we have decided to move our main campaigning week from February to May, to coincide with European Children's Heart Week. We will be taking up themes around the reorganisation of paediatric cardiac services in the UK and the inclusion of heart children in sporting activities.

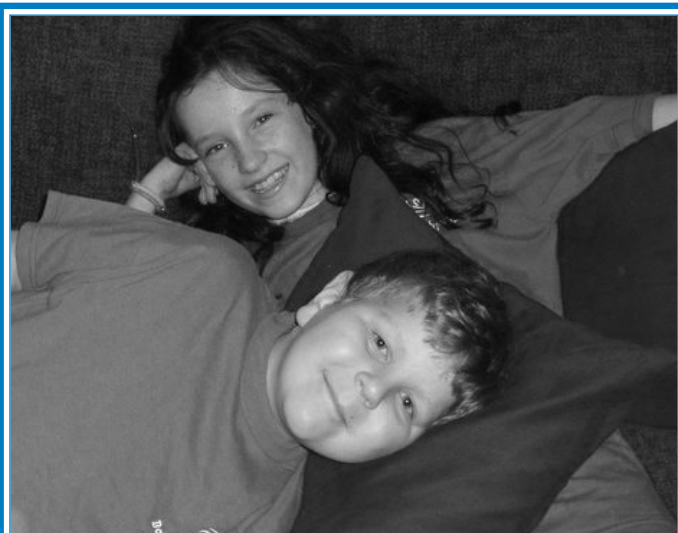
## Rare Diseases on the Agenda during the French Presidency of the EU

You may remember from a previous edition that BST was involved in a European pilot group project for rare diseases. Since July 1st, France has held the presidency of the European Union and has announced that rare diseases are a health priority during this presidency. The rare disease community is looking forward to a series of official events starting in October where rare diseases will be on the agenda.

## Enhanced Rights for Care Givers

The European Court of Justice has ruled that an EU directive barring disability discrimination in the workplace also applied to employees who cared for a disabled relative. This landmark ruling will greatly improve the rights to flexible working for parents and others who have care-giving responsibilities. It is expected that many Member States' governments will be called upon to revise their anti-discrimination legislation in order to make it comply with the ECJ ruling.

## Fundraising in Brief



*Katie and Nick, resting after Katie's walk for Barth syndrome along the Test Way in Hampshire, England.*

## Passing the Test

Katie (9), and her mum, Laura, recently walked part of the Test Way, a long distance path in Hampshire, England in aid of BST. Katie is a good friend of Nick, who has Barth syndrome. They found the way really hard going as the ground was wet and muddy and sometimes even blocked by cows! "Thinking of Nick kept me going," said Katie.

We're all extremely grateful to Katie and Laura for their efforts.

## News from the Basingstoke Area, Hampshire

*By Terri Allison, Grassroots Fundraising Coordinator*

Our families are very grateful for the wonderful way that this community has rallied around to help our cause.

BST has been very fortunate to be chosen as Charity of the Year by the Ladies' Captain of the **Weybrook Park Golf Club**, Glenna Stewart. In a recent article in the Weybrook Times, Glenna said, "The year has so far been very busy and successful

for the Ladies' section with numerous events and matches taking place. Many thanks go to all those who have contributed to my charity - the Barth Syndrome Trust. The fund now stands at £856.71."

Thank you, Glenna, Ladies and all those at the Club for your support and generosity.

A special note of thanks goes to the **Overton Methodist Community** who regularly send us a donation from the proceeds of their coffee mornings and who kindly provided us with a wonderful venue for our quizzes and the October Volunteer Meeting.

Thank you, Roy Preston, Steward at **Cannon's Social Club** for running the Race Night on our behalf, and also Sean Pickin for the music at this event. And a big thank you to the **Oakley Tennis Club**, and the **Bat and Ball Table Tennis Club**, (playing in the Channel Isles) who continue to support us.

James (age 12) and friends will be **carol singing** for BST in the village of Oakley in December. This is his second fundraiser for the Trust, and we thank the boys and wish them success.

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### A Bull Market in Bristol

Dave and Sarah Bull have been committed supporters of the Barth Syndrome Trust (BST) since joining in 2004 when their two youngest sons were diagnosed in Bristol. Dave's latest fundraising effort has been hugely successful. He has a number of BST collection boxes scattered around pubs and shops in Bristol, which have raised £3000 over the past two years and are raising awareness about Barth syndrome in the area.

"The collection tins we have are very professional and we have all the relevant permission and paperwork in place to prove who we are. It really is as easy as sitting back and watching the money come in." ~ *Dave Bull, Bristol, UK*

### No Pampering for Leigh

Leigh McNally, who works at Champneys Forest Mere, ran the Bristol Half-Marathon for BST. She is still collecting her sponsorship money. Thank you, Leigh.



### Linda Sheds Pounds to Raise Pounds

Linda, grandmother to Dillon, wanted to do something to help her grandson and others like him. She also wanted to get into the best physical shape to be able to look after and play with him. What better way than to complete a Sponsored Slim and Walkathon?

She finished on 9th September after losing over 25 pounds in 25 weeks. She also walked an amazing 264 miles equal to the entire length of Scotland, from John O'Groats to Edinburgh. Linda has raised an incredible £850 from family, friends and colleagues.

An added bonus will be that she will be looking fabulous for her daughter's wedding in December this year—congratulations to both Julie and Scott on this special occasion.

### Alex and the World Transplant Games

Alex (13) from Bristol, England, who has Barth syndrome, has not only just celebrated his 10th Heart Birthday, but he also won the gold medal in Table Tennis at the British Transplant Games (Transplant Sport UK). He has now been asked to represent the UK in the World Transplant Games in Australia in August next year. See <http://www.justgiving.com/alexsmithaustralia09>.

### News from Germany

Sonja Schlapak has been an active volunteer for the BST since joining the Trust. She has translated many resources from English to German and has been searching for new families in her region. We would like to thank Sonja's parents, Horst and Linde Witzani, for their generous donation to our Research Fund.



*Sonja's husband, Gregor, and their 20-month-old Barth son.*

Sonja, along with other families and doctors in Europe, attended the 2008 BSF Conference remotely by joining the webcast, the first live broadcast of the Conference over the internet. It was invaluable for those who were unable to travel to the Conference to be able to watch the presentations and participate online in the Question and Answer sessions.

**"I joined almost all the Web-Ex portions of the 2008 Conference. The service was excellent. It was a joy to attend the sessions. Our family is planning to attend the next conference because we want to meet all the people dedicated to finding a cure for Barth syndrome. Maybe our beloved paediatrician Dr. Blaschke will travel with us."**

~ *Sonja Schlapak*



# Barth Syndrome Foundation of Canada

By Lynn Elwood, President, Barth Syndrome Foundation of Canada

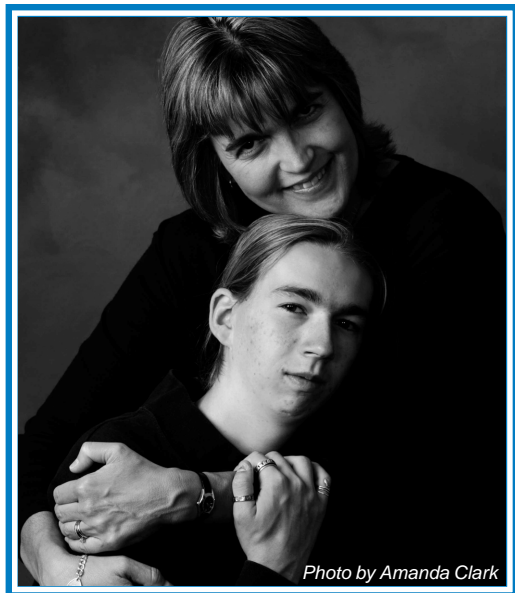


Photo by Amanda Clark

**A**t this time of the year, we find ourselves reflecting on the year and all that has been accomplished. As I look back on 2008, I have to feel this has been a great year in which an ever-expanding set of volunteers have done terrific things. Please review the Canadian update pages within this newsletter for information on a variety of areas we have been working on.

## Financial and Planning

Financially, Canada is doing well. We continue to meet or exceed our plans. This was a year in which we planned to spend more than we brought in, hoping to fund medical grants and some portions of the conference. In past years, we were able to build up a surplus that allowed us to plan for more major expenditure in 2008. We reached these milestones, and, with fundraising on target to date, the financial level of the organization is quite close to what we planned and will leave us in good position for our 2009 plans.

Our 2009 planning session is set for early November 2008. We are having the annual planning session earlier this year in hopes of helping the international Barth organizations have a better picture of our plans as they go into their planning phases. This year we are happy to have Linda Stundis, the Executive

Director for Barth Syndrome Foundation join our annual planning sessions with our Board and Executive. This is just one more sign of the international cooperation that makes the organization so strong. In the spring edition we expect to be able to share our 2008 financials and our 2009 plans.

## Canadian Newsletter

Last year we were approached by two enterprising volunteers (Marj Bridger and Les Morris) who offered to produce a small newsletter for the Canadian volunteer community. They had a vision of a colourful production that showed a lot of pictures of people and events throughout the year and gave an informal look at the types of things being done locally in Canada. The executive agreed that this would be a good way to communicate more regularly with our volunteers. We had previously received feedback from our volunteers that they wanted to know more about what we are doing, and this seemed like a great way to help.

Marj and Les created the initial version of the newsletter, and it was a great success. They set up processes so that as an event happened someone was assigned the job of quickly doing a write-up and sending this along with a few pictures to them. This made the job of putting the newsletter together easier for everyone involved.

With the success of the volunteer newsletter, we decided to expand the readership to a larger group within Canada. This newsletter does not in any way compete with the international publication. It does not cover anything medical and focuses on local information. Our dates for distribution are intentionally offset from the international newsletter so that our Canadian group is able to hear something from the organization four times a year. Some of what you will read in the Canadian section of this newsletter is similar content to our local newsletter, but even if you receive both please read on as there are always new things happening and a lot to share.

## Conference

Every second year when we have the International Conference, there is always a lot of time and effort devoted to this event. This year was no exception. We had a significant contingent of Canadian volunteers at the conference helping in all sorts of areas. In addition to physical help, we were able to provide some financial assistance, sponsoring the scientific Poster Session as well as a breakfast for families and scientists. Once again, the Conference was a great example of international cooperation.

Please see the following four pages for more information about events within the Canadian arm of the Barth syndrome family.

# Barth Syndrome Foundation of Canada

## Teamwork Goes the Extra Mile

This has been an outstanding year so far with a growing group of volunteers helping out and coming up with creative ideas in more and more areas. In the following few pages we'll share some of the significant updates from the second half of the year.



*Volunteers Carol, Mike and Bob set up registration at BSFCa's Golf Classic.*



*Volunteer Carol selling raffle tickets at the Roaring 20's social event at our 2008 Conference.*



*Volunteers Wayne, Dianne, Jan and Jack golf for Barth syndrome at BSFCa's 4th Annual Golf Classic!*

### Amazing Canadian Volunteers

*By Lois Galbraith*

What would the Barth Syndrome Foundation of Canada (BSFCa) do without its volunteers? Whenever we think of a plan or a project—we think of what part a volunteer can play! Lately our volunteers have done everything from tracking down address and websites to publishing a fantastic Canadian newsletter. Some have stuffed envelopes, sold raffle tickets and solicited or created golf prizes; while others have knitted BSFCa teddy bear sweaters, worked the golf tournament in any number of jobs, arranged for free printing of our materials, golfed in our tournament on September 8, 2008, sponsored a luncheon and planned individual fundraisers. Our volunteers continue to surprise and delight us with their love, caring, support and ideas!

We also had a significant set of volunteers helping at the BSF International Conference in Florida this summer, doing all sorts of things including arranging flights, setting up and tearing down, working for two days in the clinics, helping with photography, social events, technology, translation and family issues. Their contributions really made a difference. Our collective hats go off to this sensational set of volunteer friends!!

### Reflections on the Conference

*By Lynn Elwood*

As we reflect back on this year's International Conference, a few things stand out. First, this seemed like an even more international gathering than ever before. We had families from all over the world including some new groups from Australia, a family from Portugal and a father from Taiwan, in addition to families from the US, England and Canada. There were several new families to meet, and we really enjoyed getting to know them. We had a good turnout of Canadian families and missed those that were not able to attend. We thought of them often throughout the week.

*(Cont'd on page 27)*



(Cont'd from page 26)



*Some of the Canadian group at the Roaring 20's social event during our 2008 Conference.*



*Even at the social event, doctors & researchers from all over the world collaborate on aspects of BTHS.*

The clinics this year were better organized than ever, keeping things moving well and yet adapting to the needs of the Barth patients as they needed rests, food or just a break. The clinicians seemed to know the Barth boys and their issues very well, and this meant recommendations were more personal and valuable than ever. It also seemed that many of the tests were deeper investigations of areas that had been found in previous testing cycles. It is exciting to know that the results of these tests will further populate the international Barth Syndrome Medical Database and Biorepository and help in other areas of research.

The educational components of the conference were very strong. The family sessions were extremely informative for everyone from new parents to those that have been to several conferences. It was exciting to hear the physicians and scientists tell us about recent findings and also to hear the ground breaking cooperation that was happening down the hall in the scientific and medical sessions. We were witness to some of this interaction when we gathered with the physicians and scientists. Even at the social night, they gathered and worked together.

The volunteer efforts seen throughout the Conference were extraordinary. Several of the Canadians were among this list of volunteers, and we would like to extend our heartfelt thanks to all of the people from around the world that put together this extraordinary event.

### **Fundraising Update**

Thanks to a great many people, we have been fortunate to see success in our fundraising programs so far this year. We have done our letter writing campaign, change collection, and our annual golf tournament. In addition, we had an independent auction at Speed-O-Rama, and a number of unsolicited donations. Still to come in December is an independent Pointsettia Sale fundraiser being lead by Cathy Ritter and Audrey Hintze. We're looking forward to those beautiful flowers for the holiday season and really appreciate Cathy and Audrey taking on the organization of this fundraiser.



*(L-R) Lois and Adam thank Jamie from Tangle Creek with a little gift.*

### **2008 Barth Syndrome Foundation of Canada Charity Golf Classic (Tangle Creek Golf Club~September 8, 2008)**

*By Lois Galbraith and Cathy Ritter*

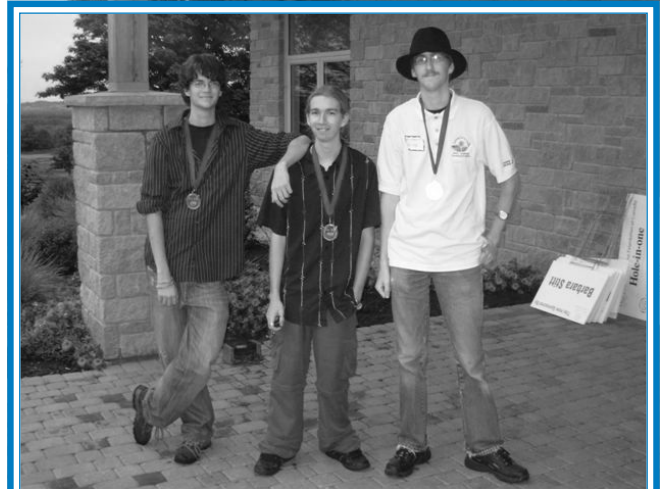
Even a steady, half-hour downpour of rain did not dampen the spirits of our loyal golfers. Our 2008 Barth Syndrome Foundation of Canada (BSFCa) golf classic was another fabulous success thanks to our golfers and our very wonderful volunteers. All of our foursome and individual prizes, as well as our silent auction items, were donated by very generous folks who believe in this day and our cause. Our corporate sponsor (Hope Aero), our cart sponsor (IQI – Ian Morris) and our luncheon sponsor (Buss Megg Society) made a huge difference.

*(Cont'd on page 28)*

(Cont'd from page 27)



*(L-R) Elizabeth from Barrie is joined by Sharon, Jan and Joanie who came all the way from Florida to golf for Barth at BSFCa's 4th Annual Golf Classic.*



*(L-R) Ryan, Adam and Robert, a few of our Barth guys at BSFCa's 4th Annual Golf Classic—as volunteers and golfers!*

We had a wonderful day of golf at challenging Tangle Creek Golf Club where we saw great shots, rain, long drives and tricky putts. The day was also filled with silent auction bidding, wonderful camaraderie, prize selecting, presentations and great food. Jan Kugelmann, Sharon Olson and Joanie Weaver from Florida golfed with us this year and made it an international event.

The day raised \$24,300 for our BSFCa programs and we sincerely thank all of our hard working volunteers, our dedicated sponsors and all those great people who golfed and who donated the myriad of prize items. Our 5<sup>th</sup> Annual Golf Classic will again be held at Tangle Creek on Monday September 14, 2009. See you there!!

### Awareness

*By Lynn Elwood*

There are many forms awareness takes. BSF of Canada has worked on phone and mail campaigns to physicians, conferences and other physician awareness events. These efforts continue and are resulting in an increased number of physicians across Canada who are now aware of Barth syndrome and the organization.



*Picture of Barth backpack going shopping. Barth goes green!*

This year, we have also undertaken some general awareness campaigns. We have created a Photo Awareness Contest. We have a number of Barth bears - little stuffed bears with hand knit sweaters with the Barth logo on them. These we give to anyone who wants to take them around with them. This could be families with young children, people who travel or just those who want to have a bear for comfort. Our volunteers have done a great job to make each of them individual and special.

People are encouraged to take pictures of the bears or any of the Barth syndrome logos in different places, doing different things, showing our logo and name to help raise awareness about the condition (of course they are also encouraged to take some material to share if people ask for information). They send the pictures in and we will feature them in our Canadian newsletter. This is a fun little program that also helps to raise awareness within the general public. Although this has been introduced within Canada, we'd love to see it go international, so if you are interested in participating please feel free to send us photos at [lelwood@barthsyndrome.ca](mailto:lelwood@barthsyndrome.ca).

(Cont'd on page 29)



*Lindsay and her team create a Barth Syndrome Foundation of Canada brochure and presentation.*

Awareness is also spread through community and charity support. On a number of occasions we have assisted high school, college and university students in research projects they have chosen to do on Barth syndrome or our organization. Recently, we were approached by an Ajax student, Lindsay, who needed to do a project on a local charity. It was great news that she and her group found BSF of Canada in their research of Canadian charities and chose us for their project. Over the span of a few weeks, they did considerable research on Barth syndrome and the Barth Syndrome Foundation of Canada. They created a sample brochure on the condition and the organization and a presentation to accompany it. The questions they asked during their research were interesting and insightful.

This talented group received a very high mark on their initial presentation and may be invited to present to a higher level in the Youth and Philanthropy Initiative competition, where the chosen charity group wins \$5,000 towards their charity's programs. Whether they win the contest or not, this project has raised awareness of the condition among a whole new set of people in the area.



*"...I feel so appreciated for my efforts that I look forward to that tournament every year."*

### **Why I Volunteer for BSF of Canada**

*By Penny Fink*

I met the grandson of some very old and dear friends about 12 years ago. He was a sweet little boy, about 6 years old, with a smile that brightened the room, and the most beautiful eyes that looked at both grandparents with love and adoration. He sat with his grandma and I listened to them reminisce about what a great shot she was with the rifle, knocking a red squirrel out of a tree just for chittering at them. From subtle things that were said, I realized there might be something 'different' about that little boy, and when I had the opportunity, I asked. That's how I learned about that insidious disease known as Barth syndrome. I wanted to help, but really didn't know how, until my friend Lois and all of the people involved in the Barth Syndrome Golf Tournament brought me in! Did I mention?...I'm NOT a golfer, but I went that first year...helped a little on the registration desk, and then headed out on the course! Oh my goodness, I was horrid, but I felt I was helping a good cause, and my little buddy was alive and growing fast into a sweet young man, thanks to the research that was opening up ever more advances into what Barth syndrome was all about.

The next year, I begged off golfing (I'm sure the other three of the previous foursome were grateful) and volunteered on the registration desk, meeting amazing people, both volunteers and golfers. We laughed, chatted and got this fun show on the road. We set up for the silent auction, got the prizes in order, and then I headed out to the hole-in-one post, where the real golfers tried their best to do what I felt was the impossible!! And some succeeded! What fun! I can't wait to be back there again this year. My tiny contribution is nothing compared to the amount of work done by the front line workers, but I feel so appreciated for my efforts that I look forward to that tournament every year, and I look forward to seeing my Barth Boy, alive and healthy, as he starts off to college this fall.





# The Barth Trust of South Africa

By Jeannette Thorpe, Chairperson, Barth Trust of South Africa



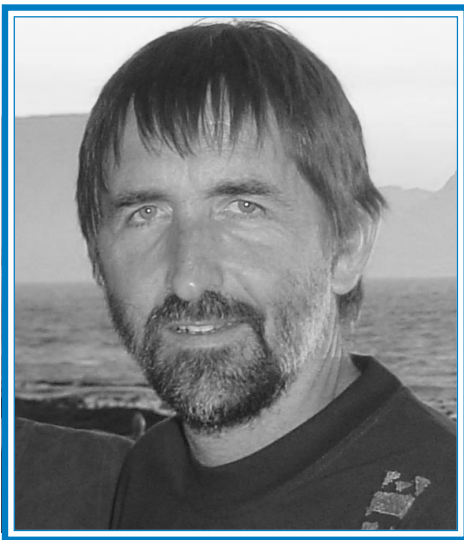
It was with great sadness that I was unable to attend the Barth Syndrome Conference this year. However, Dr. Rik De Decker very graciously agreed to represent the Barth Trust of South Africa and his report is below. This visit introduced Dr. De Decker to the new blood spot test, which could be of considerable importance in South Africa.

I am pleased to report that Dr. De Decker will be presenting on Barth syndrome at the South African Heart Association Congress in November (the second presentation on Barth syndrome in South Africa) and will have an abstract published in the South African Heart Journal. This will be the first clinical abstract to be published in a South African journal.

Next year, I will be working to raise awareness in the public arena and am busy looking at the most suitable magazines and other media to use.

Thank you Dr. De Decker for your representation at the Conference and for your support here in South Africa!

I would like to take this opportunity of wishing everyone a very happy December holiday, and may 2009 bring peace and joy to you all!



## Dr. Rik De Decker's Report :

I had the privilege of attending the 2008 Barth Syndrome Foundation International Conference in Clearwater, Florida, USA, where I was representing the Barth Trust of South Africa. This was my second opportunity to attend an international Barth syndrome meeting, and once again I was impressed by the breadth and depth of the presentations.

From a South African perspective, this meeting was extremely significant. The Dutch team presented their landmark paper on the bloodspot screening test for Barth syndrome (BTHS). The senior author, Dr. Willem Kulik discussed a method that determines the ratio of monolysocardiolipin to cardiolipin, a test shown to be 100% sensitive and specific. Significantly for us in South Africa, the test requires only a small spot of dried blood on filter paper, which is then readily mailed by ordinary surface mail to the laboratories in Amsterdam. Their test has opened an opportunity for a simple BTHS screening test for boys from South Africa with cardiomyopathy or other signs suggestive of BTHS. Until now, diagnosis was based on clinical criteria, while definitive genetic testing in South Africa was fraught with logistic and procedural problems.

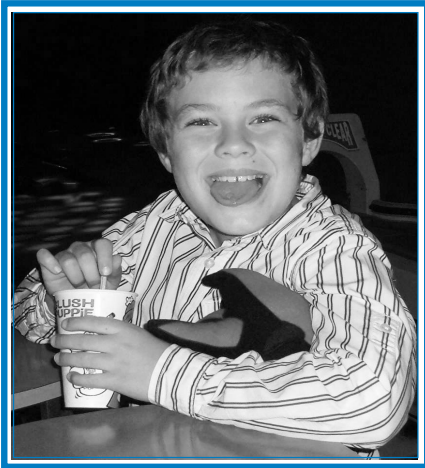
At the meeting, I discussed testing possibilities with Dr. Kulik and head of the Dutch team, Prof. Ronald Wanders, and already we have reaped the rewards of this collaboration. A young boy, who presented critically ill at Red Cross Children's Hospital in August with cardiomyopathy and found to have 3-methylglutaconic aciduria, was screened by this method. Within 14 days, we had confirmation that he did **not** have Barth syndrome. Unfortunately, the boy died of complications of his illness, but the negative test result allowed our genetic counsellors to reassure his parents of the absence of any possibility of Barth syndrome in his twin brother, who is asymptomatic.

I should like to thank Mrs. Jeannette Thorpe of the Barth Trust of South Africa, for arranging my visit to the conference and for the organisers of the conference for a very stimulating and rewarding experience. Many other informal collegial connections were made or strengthened, and these may assist us in the future to better diagnose and care for patients with Barth syndrome.

# Sibling Spotlight

## Featuring friends from around the globe

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



**Name:** Jay

**Age:** 9

**Where are you from?** Ayrshire in Scotland.

**What are your hobbies?** Running and football.

**Affected sibling?** Alfie (8)

**What do you like doing with your brother?** Football and cycling down the beach.

**If you met someone who had just found out that their brother had Barth syndrome, what would you say to make them feel better?**

It is something special so be proud of it.

**What does BSF/BST mean to you?**

It helps so I think it is brilliant!



**Name:** Beth

**Age:** 15

**Where are you from?** St. Petersburg, FL

**What are your hobbies?** My favorite hobbies are swimming and outdoor activities, reading, and playing my violin and piano.

**Affected siblings?** Benjamin (13), John (7), and Daniel (2)

**What do you like doing with your brothers?** We do what a normal family would only less rough. We play soccer, catch, we go fishing and play games of all sorts. We enjoy looking for small reptiles such as snakes and lizards, and we love to go to the beach.

**If you met someone who had just found out that their brother had Barth syndrome, what would you say to make them feel better?** I would tell them that everything will be okay because they are not alone, and there are doctors who know how to help him stay healthy and strong.

**What does BSF mean to you?** Well it means that we aren't alone in this and there are others that feel the grief and stress of having such an illness in their family. It is important to me because I know I'm not the only one who has to deal with the stress, and I have people I can go to who understand.



**Name:** Stephanie

**Age:** 25

**Where are you from?** Barrie, Ontario, Canada

**What are your hobbies?** I enjoy running, reading, and spending time with my family.

**Affected sibling?** Ryan (17)

**What do you like doing with your brother?** Ryan and I enjoy many things together, such as going to the cottage, playing Magic, watching movies, and reading.

**If you met someone who had just found out that their brother had Barth syndrome, what would you say to make them feel better?** There were differences that we had to deal with growing up as a family, but I still had (and have) as much fun with Ryan as I do with my non-Barth brother, Andrew.

**What does BSF/BSFCa mean to you?** Brings research, education, and support to affected boys and families around the globe.



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 Hatfield, Louise  
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 Heinrich, Lee  
 Hill, John  
 Hill, Rick  
 Hintze, Audrey  
 Hocalok, Adrienne  
 Hocevar, Frank  
 Hocevar, Helen  
 Hollands, Dennis  
 Hollands, Joan  
 Holmes, John  
 Hone, Barbara  
 Hone, Chris  
 Hone, Susan  
 Hope Aero,  
 Hope, Christine  
 Hope, Harry  
 Hope, Helen  
 Hope, Michael  
 Hope, Robert  
 Hope, Ruth  
 Hope, Terry  
 Howard, Sharon  
 Hudson, Mrs. E.  
 Hugget, Fred  
 Hughes, Cathy  
 Hughes, Ron  
 Humphries, Jack  
 Humphries, Jan  
 J&B Customs  
 Jeffery, Elaine  
 Jeffery, Jeff  
 JonesDeslauriers Ltd.  
 Karolidis, Paul  
 Kellar, Chris  
 Kelly, Hal  
 Kemp, Bill  
 Kennington, Paul  
 King, Gail  
 King, Myles  
 Kingshot, Gavin  
 Kirsch/Gidaro  
 Kraljic, Andrew  
 Kraljic, Tom  
 Kritschgau, Rick (Vision 2000 Travel)  
 Kugelmann, Steve  
 Kugelmann, Jan  
 Kumar, Sarbjeet  
 Kumarasamy, Muhunthan  
 Kuzik, Brian  
 Labelcraft Products Ltd.,  
 Lamb, Doug (Exceltec Auto Services)  
 Lamorie, Bruce  
 Lant, Tony  
 LeBlanc, Jennifer  
 Leckey, Jim  
 Leighton, Jeannine  
 Leighton, Keith  
 Lincoln Electric  
 Lindsay, Sue  
 Lockhart, Paula  
 Loos, David  
 Loos, David  
 Lunn, Joan  
 Lyall, Doug  
 MacDonald, Carol  
 MacDonald, Fred  
 MacDonald, Jodi  
 Macewan, Alistair  
 Macewan, Chris  
 MacKay, Bruce  
 McGill, Cheryl  
 Malcolm, Diane  
 Malcolm, Martin  
 Malfara, Frank  
 Mann, James  
 Mann, Ruth  
 Martin Laneau, Liz  
 Masterson, Moira  
 McCurdy, Kate  
 McCurdy, Steve  
 McGill, Steve  
 McGuinness, Celia  
 McGuinness, Celia  
 McJannett, Andy

McJannett, Bob  
 McJannett, Rob  
 McJannett, Susan  
 McKee, Bev  
 McKercher, Don  
 McKercher, Ingrid  
 McShane, Harvey  
 Megelink, Jasper  
 Megelink, Mary  
 Mendes, Lynsi  
 Merrill, Debra  
 MGM Insurance Agency Ltd.  
 Millar, Margaret  
 Millar, Ronald  
 Miller, Pickard Law  
 Milne, Peter  
 Miss Classic Car Club  
 Molinaro, Elvi  
 Morris, Dianna  
 Morris, Elsie  
 Morris, Ian  
 Morris, Les  
 Morris, Pam  
 Mullen, Leatta  
 Murphy, Tony  
 Nagel, Erna  
 Nagel, Siegfried  
 Nagel, Thomas  
 Naraine, Christopher  
 Newfeld, Beth  
 Newfeld, Jeff  
 Noddle, Norm  
 Norwell, Jeff  
 Novopharm Ltd.,  
 OddBall Customs/ Stoney  
 Olorenshaw, Neil  
 Olson, Sharon  
 Paczkowski, Taisia  
 Pape, Aaron  
 Patnick, Barbara  
 Pearce, Bev  
 Pearce, William  
 Performance in Motion  
 Perkin, Phyllis  
 Pick, Brian  
 Pike, Pam  
 Pitkethly, Maureen  
 Poitras, Mike  
 Poitras, Sandi  
 Poole, Bob (Aerostructural Inc.)  
 Post, Michael  
 Power, Carolyn  
 Quackenbush, Carolyn  
 Quackenbush, Earl  
 Quaker State  
 Rantz, Rick  
 Raso, Joe  
 RBC Foundation  
 Redpath, Sydney  
 Ritter, Andrew  
 Ritter, Carole  
 Ritter, Cathy  
 Ritter, Chris  
 Ritter, Ryan  
 Roberts, Marlowe, Jackson, Jackson & Assoc.  
 Robinson, Elizabeth  
 Ross, Barbara  
 Roy, Larry  
 Royal & Sun Alliance  
 Rush, Aaron  
 Russ Baxter & Arther Martin Model Engine  
 Rutenberg, Karen  
 Sandelovich, Joyce  
 Sandelovich, Robert  
 Sawh, Harold  
 Sawh, Ruby  
 Schuller, Dana  
 Schuller, Dennis (Aviall Canada Ltd.)  
 Scothorn, Pam  
 Scott, Bob (Mx Aerospace Services)  
 Scott, Jeffrey  
 Sedefian, Lynda  
 Selkirk, Kim  
 Sharpe, Wade  
 Sheppard, Jamie  
 Simone, Charles  
 Simsons, Andy  
 Simsons, Joyce  
 Sisson, Lindsay  
 Sisson, Paula  
 Sivapathasunderam, Dushyanthan  
 Skopit, Barry  
 Slepkov, Martin

Sluzar, Daniel  
 Sluzar, Mark  
 Smith, Glenn  
 Smith, Ted  
 Smolic, Alex  
 Smolic, Joe  
 Snowden, Mary  
 Souter, Caroline  
 Stabb, Susan  
 Steamwhistle  
 Stevens, Mike  
 Stitt, Barbara  
 Stoll, Brian  
 Storey, Andrew  
 Storey, Dick  
 Storey, Janis  
 Stratford Motor Prod  
 Street Classics Cruise  
 Stundis, Linda  
 Sturup, Penny  
 Sturup, Penny  
 Sunational Landscapes Inc.  
 TD Trust Bank - Havelock, ON  
 Tech Web Printing  
 Thomas, Brian  
 Thorpe, Jeanette  
 Timpleck, Barry  
 Tjart, Gwen  
 Tjart, Richard  
 Tomlinson, Annette  
 Tomlinson, Brian  
 Tomlinson, Danny  
 Tomlinson, Shannon  
 Torrence, Erin  
 Toth, Matt  
 Tramp Warner  
 Trillium Gift of Life Network  
 Trim, Norma  
 Trim, William  
 Trueman, Carole  
 Tsilikas, Alana (Kelsey's 7066)  
 Turner, David  
 Turner, Lynda  
 Turner, Ron  
 Tweed, Scott (Medical Post)  
 Tweed, Sue  
 United Way of York Region  
 Vandemeer, Carl  
 Vanderwater, Barbara  
 Vella, Betty  
 Vilneff, Bill  
 Vilneff, Rita  
 Vine, Edward  
 Vine, Rosa  
 Wallace, Gary  
 Waller, Cliff  
 Wansbrough, Gillian (Medical Post)  
 Warren, Janet  
 Warren, Jerry  
 Weaver, Joan  
 Webb, Lindsay (Lindsay Webb Financial Inc.)  
 Weeks, Jane  
 Weeks, Ken  
 Wegman, Gelja  
 Wegman, Rick  
 Welch, Dave  
 Weller, Sharon  
 White, Leone  
 White-Markham, Andrea  
 Whitmore, Connie  
 Wild, John  
 Wilkins, Mike  
 Wilkins, Sue  
 Wilks, Bruce  
 Wilks, Carol  
 Wilks, David  
 Wilks, Dennis  
 Wilks, Helen  
 Wilks, Maddy  
 Williams, Matha  
 Wilson, Ron  
 Wivcharyk, Lubow  
 Woodcock, Sharon  
 Woodcock, Roy  
 Wuthrich, Grace  
 Young, Dorothy  
 Young, Lenore  
 Young, Ron  
 Ziicor, Laura



# 2009 Request for Research Proposals

The Barth Syndrome Foundation, Inc. (BSF) and its affiliates are pleased to announce the availability of funding for research internationally 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 around the world. 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. 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 and those of our three international affiliates will make the final funding decisions for the grant applications. Please review our “Grants Awarded” webpage for a listing of grants that BSF has awarded to date.

## Deadline

The deadline for submission of completed research grant applications from interested researchers is **October 31, 2009**. Grants will be awarded early March 2010.

## Contact Information:

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



Barth Syndrome  
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