

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

## Highlights of Interest

- BSF featured on NBC TODAY Show
- BSF awards 2008 research grants
- BTHS Mouse Model
- Personal Message from Dr. Peter Barth

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## BSF featured on NBC TODAY Show

*By Kate McCurdy, Board Member, Barth Syndrome Foundation*

“Turning Anguish into Action” is what NBC’s TODAY Show entitled their segment featuring Barth syndrome that aired in the US on February 16, 2009, and we think that it is a very fitting title for much of what we at BSF do. We take the situation that we all have been dealt and turn it, as best we can, to good—scientific and medical progress and support of others.

One way we all do this is by seizing opportunities to educate the medical and scientific communities as well as the public about the rare disorder that is so important to all of us. As a result of a long string of coincidences and contacts, we (Will, Kate and Steve McCurdy) were fortunate enough to be offered the chance to appear on the TODAY Show a few months ago. We took a deep breath and decided that it was well worth doing for the cause, even though the experience took us WAY out of our comfort zone. In addition to the TV appearance, a related article was published in the on-line version of PARADE Magazine (“Fighting a Rare Illness—Together” by Meg Massey). Taken together, these two media outlets offered incredible exposure for our rare disease. The TODAY Show



*(L-R): Kate McCurdy, Steve McCurdy and Susan Axelrod (of CURE Epilepsy) being interviewed by Al Roker on the TODAY Show on February 16, 2009. (Photo courtesy of NBC TODAY)*

is seen by an average of 6 million viewers each day, and PARADE Magazine has a huge readership of something around 75 million people (though we were only in the on-line version, not the print version that is inserted in so many Sunday newspapers in the US, and so the readership was considerable less for our piece).

*(Cont'd on page 6)*

## Barth Syndrome Researchers Secure NIH Funding

During this last year, several Barth syndrome researchers have received NIH grants to continue their studies on Barth syndrome. These awards are for several years each, and the funds made available are usually in the range of several hundred thousand dollars. Dr. Mindong Ren recently received an R01 award for “Barth syndrome: A model for investigation the role of cardiolipin in mitochondria.” Dr. Miriam Greenberg received an R21 award for “Synthetic lethal interactions in Barth syndrome.” Dr. Steven Claypool, who spoke at the 2008 Barth Syndrome Foundation International Conference, received an R00 award for “Characterizing tafazzin and Barth syndrome mutant tafazzins.” Drs. Greenberg and Ren are previous or current BSF Research Grant recipients. Congratulations to these talented and hard-working researchers on their public awards and recognition.



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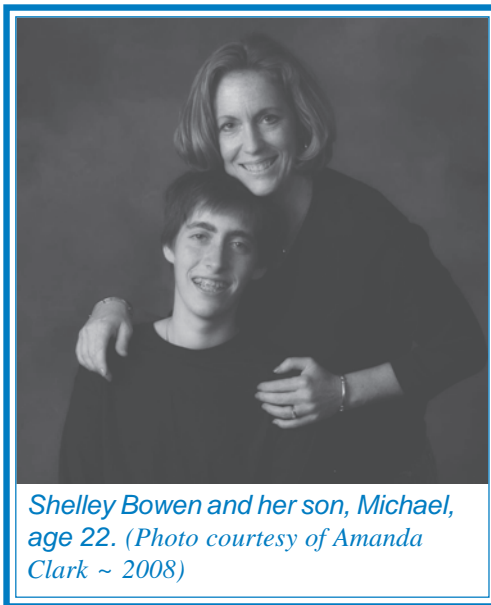
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# President's Letter

## Words of Wisdom

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



*Shelley Bowen and her son, Michael, age 22. (Photo courtesy of Amanda Clark ~ 2008)*

If there is one thing that I have learned in this life, it is to pay attention. Life happens and we are here for the journey. If we are brave enough to open our hearts to love, we will indeed at some point be confronted with grief. I once heard that the depth of grief mirrors the depth of love we allowed ourselves to feel. Grief is the price we pay for the joy we received through the blessing of being able to love.

Dr. Peter Barth has written a lovely letter for this edition of the newsletter. If you know me, you are well aware of how much Dr. Barth means to me as a friend and as a mentor. He gave me direction when I was lost. He gave me hope when I was in despair. Most of all, he has been capable of succinctly articulating thoughts where words have failed me. When I first met Peter Barth in 1996, we had a very long conversation about what I had gone through

with my children and similarities of his journey with Barth syndrome from a physician's perspective. He said, "*The cruelest irony of Barth syndrome is how deceptively healthy these boys appear.*" What an ah-ha moment! In one statement, he summed up the challenge I had confronted as a mother. How could a child who looked so good get so sick? I cannot begin to tell you how many times I heard "*He looks fine*" about my son when in truth he was far from fine.

Those words of wisdom never seemed more appropriate in this community than they have over the past year. In January, we were all dealt a blow with the loss of Michael Reece, a 10 year old boy who was seemingly healthy but died on his 10th birthday. In August, yet another blow to our community came when Christian Oldewage passed away, a child who was doing well for some time but worsened as his life went on. Then, just last month, yet another blow when Michael Telles, a boy of 7 years, died. I sat aside four other parents within our community during his funeral, including Casie Oldewage and Greg Holly who themselves had lost children to Barth syndrome. There we were at a funeral of a boy who just a week prior seemed completely fine. There we were watching his parents mourn the loss of their child, when just a week prior everything was normal in the Telles home.

As hard as I tried, I could not make sense of this. What did we miss? Where was the message in all of this? I believe there are messages from which we can learn if we pay attention. Then the words of Peter Barth came to me "*The cruelest irony of this disease is how deceptively healthy these children appear.*" It was then that I realized the message... There is no such thing as a mild case of Barth syndrome. It is stealth; therefore we are required to be vigilant and pay attention. It is unpredictable; therefore we are required to be proactive. It is obscure; therefore we are required to be advocates.

I then heard the priest say, "*It is human nature to think of what could have been, but I encourage you to consider what happened. As we see a blossom that has fallen to the ground, we could think what a pity or what a splendid peach this blossom could have been. We could think of this blossom's role as being incomplete and fail to appreciate what it did.*"

(Cont'd on page 3)

(Cont'd from page 2)

*In its time, this blossom made the air more fragrant, it pollinated the trees and it gave the observer a sense of splendor in its fullest of beauty.*" I felt tears well up in my eyes as I realized how very blessed I have been to know these and other boys who have lost their lives to Barth syndrome.

As I thought of every boy and family that I have come to know in this group, I considered myself blessed. I considered those who had died and those who continue to courageously fight to live every day of their life to the fullest. Then, suddenly, I came out of my daze to hear Michael's mom, Michelle say, *"My son had Barth syndrome and he died because of Barth syndrome. For this reason I intend to do everything I can to ensure that no other parent has to go through this ever again."* I felt a wave of gratitude, not just to Michelle and Michael for their vow to my family and every other family in this group, but also to every other person in this group who reciprocates Michael and Michelle's sentiment.

I was humbled to think of all those who have committed themselves to this cause. I thought of every doctor, researcher, parent, grandparent, donor, friend and volunteer who is committed to this common cause. I have made partners who, out of the hardest of circumstance, have become my dearest of friends. As difficult as it seemed to comprehend, I realized how blessed I have been to witness the greatest compassion and kindness humanity has to offer. I would gladly trade this all in for keeping every child safe and return every child that has succumbed to this dreadful disease back to the arms of their parents. While I cannot return every child to the arms of his parents, I can do all within my power to change the future.

I glanced to my left and felt honored to be seated with several of these partners in this community; Greg Holly, Mike Wilkins, Jan Kugelmann and Casie Oldewage, and I looked at the rows ahead at Michael and Michelle's family. Once again another of Peter Barth's observations came to mind. He said, *"In all of the years that I have worked with disease advocacy groups I have never seen one that compares to this. I find myself surrounded by people who are working together to make a difference. There is no ego and there is no bitterness. The overwhelming commitment of teamwork and optimism is the evident tone throughout this community."*

Today I learned of the death of a father of one of our boys, John Grzesiak. He was an amazing man, a devoted father and a loving husband. John's passing brought to mind a statement my son once made, *"I am not immortal, everyone dies. I don't know when but I do know that I will die. So, I intend to make the most of every breath that I have between my first and my last."* That is how John lived his life. Just like my son, John and every other boy I know or have known in this group have indeed lived life to its fullest. As Peter Barth observed, this is a group of great hope and optimism. Granted we grieve, but that is only because we dared to love. As much as we live for today, we collectively fight to ensure our ultimate vision of a future in which no one will die or suffer because of Barth syndrome. To do that, we must remember there is no such thing as a mild case of Barth syndrome.

Thank you to all who have cared enough to share in this journey, and I hope that we will all soon celebrate our ultimate vision together.



**"In all of the years that I have worked with disease advocacy groups I have never seen one that compares to this. I find myself surrounded by people who are working together to make a difference. There is no ego and there is no bitterness. The overwhelming commitment of teamwork and optimism is the evident tone throughout this community."**

*~Peter G. Barth, MD, PhD*

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# A Community of HOPE

By Linda Stundis, Executive Director, Barth Syndrome Foundation

Growing up, I studied classical music, and one of my favorite pieces was an oboe concerto by Tomaso Albinoni. In this haunting piece, there is a point at which the oboist holds the note for so long, you feel as if you need to catch your breath just listening to it; and it always seemed to me that this was the place where all of life is lived—all the hope and all the fear—in that long, quivering note. In the past several weeks, I've listened to this concerto again and again...

In my first newsletter article last November, I wrote about *An Extraordinary Community with a Profound Sense of Urgency*. For this newsletter, once again, I am drawn to a theme of community—*A Community of HOPE*—an extraordinary community that has the courage to be afraid, yet dares to hope...

It is so profoundly clear that within the BSF community, all the children who have left us, who have been wise beyond their years, heroic beyond their years, have left behind a legacy of hope and love.

BSF was founded upon this legacy, and over the past eight years the accomplishments have been tremendous, and are a tribute to all the families, physicians, scientists, donors, and volunteers. Dr. Barth says it most succinctly, *"I feel both humility and pride at the sight of what BSF has become."*

But the urgency is profound, and we must continue to push forward with both strategic deliberation and alacrity. We must continue to advance the science. We are poised once again for important breakthroughs, and much of this newsletter is dedicated to Barth syndrome (BTSH) research. We must continue the work to develop and publish treatment guidelines—no easy task for a multi-system rare genetic disease, but one of our most important. Kate McCurdy, Matt Toth, and I will be at the National Institutes of Health in June, and we will be seeking their advice as to how best to proceed with the development of guidelines. We must advance the work being done with the Barth Syndrome Registry and DNA Bank, key to advancing much of the science and certainly to finding a cure for BTSH. To this end, I was at University of Florida in late January, and I meet regularly with Carolyn Spencer, MD, Co-Principal Investigator. Beginning in June, Shelley Bowen will be devoting time every week to help Melissa Maisenbacher, MS, CGC, Pediatric Genetic Counselor, enter all the outstanding medical records into the newly designed database. We must continue to advance physician awareness, to foster the identification of new BTSH families, and to ensure that the BSF community continues to be both engaged and well-served. Finally, we must raise the funds necessary to advance all of our programs and initiatives—a task in this difficult economy that will require the help of everyone who knows and understands BTSH, as well as new donors interested in helping us change the world of BTSH.

So much extraordinary work has been done, but so much more remains if we are to one day find a cure for this dreaded disease. The challenges are great, but the power of a committed, engaged, energized community is greater.

It is a privilege to work with and for each and every member of this extraordinary community.

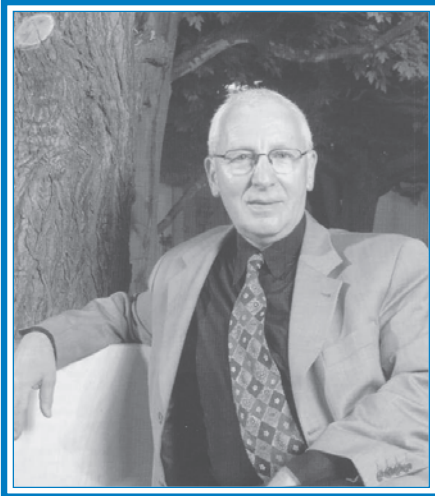


Photo courtesy of Amanda Clark ~ 2008



# A Personal Message from Dr. Peter Barth to the Barth Syndrome Community

By Peter G. Barth, MD, PhD, Emeritus Professor in Pediatric Neurology, Emma Children's Hospital, University of Amsterdam, Amsterdam, The Netherlands



It was a long time ago, back in 1972, that I had my first encounter with Barth syndrome, then a disease without a name. My first acquaintance was a boy, just one year old when he was brought to the pediatric ward of my hospital in Amsterdam as an emergency. He had a history of poor growth, weakness and cardiac disease from birth. On admission he was very ill, had high fever and almost zero neutrophil white blood cells. Despite immediate treatment for his infection he died that same night. Autopsy showed that he had a decompensated dilated heart. But even with the report of the microscopy of the heart by the pediatric pathologist we failed to name the disease. When I talked to the boy's parents they told me that there were other families related to theirs with similar histories of affected boys, all being weak, all dying early either from infection or heart disease.

Our next challenge came two years later when a full cousin of this boy died in our hospital at the age of three days from a dilated heart and infection. At that moment I realized that even routine pathology would not help us with answers here and I decided to obtain a small piece of his heart muscle for electron microscopy, immediately after he died. This is a common procedure nowadays e.g., as part of a biopsy

procedure; then it was an experimental approach to an enigmatic condition. Having done this we were able to see the cells of the heart muscle, unharmed from postmortem decay, as they revealed the first glimpse of what was wrong: the mitochondria had a highly abnormal structure. Two more boys were seen, for the first time presenting in a more stable condition, and they enabled us to confirm by additional studies the abnormality of their white blood cells and the involvement of their energy metabolism in muscle, the latter with the help of Jasper Scholte, an expert on mitochondria from Rotterdam University.

By 1983 we were ready for a comprehensive report on this condition which we called X-linked mitochondrial disease. Later on it came to be known as Barth syndrome. The fact is however that many have worked to get hold of this disease. Richard Kelley discovered the 3-methylglutaconic aciduria and emphasized the growth delay. Peter Vreken and Fredoen Valianpour working in the lab of Ronald Wanders in Amsterdam and Michael Schlame working in the USA independently and almost at the same time discovered the deficiency of cardiolipin. Piet Bolhuis used DNA samples from the family above to localize the gene defect to the long arm of X-chromosome. Sylvia Bione working in the lab of Daniela Toniolo in Pavia (Italy) finally identified the gene underlying the disease on this part of the X-chromosome. At this moment scientists from different disciplines and different countries are making efforts, not only to discover more facts, but with the ultimate aim of developing better and more specific therapies.

I had the privilege of meeting Shelley Bowen for the first time in 1996 when we met at my hospital in Amsterdam, together with Michael Bowen. For Shelley Bowen this trip was the starting point for her effort to get all families together in one grand organization that has ultimately become BSF.

BSF has become great and astonishingly successful in its efforts to raise funds to support scientific work on Barth syndrome, to promote the understanding of this disease among the medical profession and to help families cope by mutual contact, advice and empathic support. Being one of the pioneers in the study of this disease I feel both humility and pride at the sight of what BSF has become.

For many of the families the time ahead will be more difficult because of the economic crisis, which complicates their medical problems. I wish all, and especially those affected by the crisis, all the strength they need to work for a healthy and happy future.



# BSF featured on NBC TODAY Show

(Cont'd from page 1)

Our family story about Barth syndrome is similar to some others. As described in the PARADE article,



Will, age 3. (Photo courtesy of the McCurdy Family)

*"From the day he was born in 1986, Will McCurdy was a bright, engaging and alert child. But when he reached the age at which other babies began to rollover by themselves, he did not. Then, as his peers progressed to sitting up, he also didn't reach that milestone. His parents, Steve and Kate McCurdy of Westchester County, N.Y.,*

*took him to physicians up and down the East Coast to find out what was wrong, but none could identify the exact problem.*

*Two years later, Will came down with what the McCurdys thought was a bad chest cold; what's more, they noticed that his heart was racing. When they took him to their pediatrician, he sent them to the ER because he was concerned that the toddler might have an infection. At the hospital, they received some shocking news: Will was in heart failure and might need a heart transplant.*

*'I remember wondering in the ER whether all this might lead to something bigger and broader,' says Kate. She was right.'*

We knew that we wanted to meet other families, but we knew of none. So when we found out on the internet that Shelley Bowen, Sue Wilkins and Anna Dunn were organizing the first-ever Barth syndrome family meeting in June 2000, and Dr. Richard Kelley and Dr. Peter Barth were holding a simultaneous meeting for doctors and scientists, we knew we wanted to be there and to become active and involved in it all. From these meetings, the Barth Syndrome Foundation, Inc. was born... and anguish was turned into action.

As Steve said to Al Roker in the interview on the TODAY Show, *"I think any doctor will tell you that there's nothing as powerful as a parent with a sick child who's determined to find a solution. The key... is to make sure that you build a partnership with the doctors and make sure that you build a partnership with the scientists. But first, you've got to find a way to bring them all together because... this is a rare disorder... One new family might have the key to the solution—the scientific solution—so it's important for us to bring all the families together and make them part of the Foundation."*

The response to the TV segment and the magazine piece was phenomenal. Google tracks what key words are typed into their on-line search engine every day, and on the day that the TODAY Show aired, "Barth syndrome" was the fifth most

frequently searched term in the world! Barth syndrome search activity was so hot it was called "volcanic", and the Barth Syndrome Foundation website received over 11,500 hits that day alone. In addition, once people found our website, 60% of them spent more than 5 minutes there, with nearly 40% spending more than 10 minutes... so they really looked at some of our material. 65% of the visitors that day viewed two pages or more of our website. Clearly, awareness of our small disease was raised and information disseminated.

Who knows what may come of it all. It is difficult to know what seeds have been planted and what fruit might be born. What we do know is this. BSF has received 12 inquiries from families who think that their child *might* have Barth syndrome. Not all of these individuals will be found to have the disorder once tested, of course, but some probably will. We (the McCurdys) decided that if we could help just one family by exposing ourselves to this media coverage, then it would all be worthwhile. We are very glad that we stepped up to this challenge on behalf of all Barth syndrome families and turned anguish into action.

(As a personal postscript to our five minutes of fame, we must say that one of the fun side benefits of our appearance was to witness how big-time television works behind the scenes. NBC insisted on sending a limo to pick us up in the morning in order to make sure that we were at the studio in NYC on time. Then we were taken to the Green Room where we were introduced to Bill Keller, the Executive Editor of *The New York Times*, who was to be on the show to talk about his new book about Obama and where we also met Susan Axelrod who was on the same segment we were. She is the founder and President of CURE Epilepsy and is a wonderful woman and mother who has become a real force in Epilepsy research as the result of the fact that her daughter has the disease. Of note, she also is the wife of David Axelrod, President Obama's Senior Advisor. Next, we were taken to "hair and make-up" where we each were put through the drill and where we saw Jane Fonda (along with her entourage and her little dog) and others who were guests on the TODAY Show the same morning. It was pretty interesting all around and wonderful to realize that Barth syndrome plays in the Big Leagues!)



To watch the entire TODAY Show segment or to read the complete PARADE Magazine article, please go to [www.barthsyndrome.org](http://www.barthsyndrome.org) and scroll down to the bottom of the Home Page to the What's New box. There, you will find links to both.

# BSF Board of Directors Welcomes Marc Sernel

By Stephen McCurdy, Chairman, Board of Directors, Barth Syndrome Foundation



I could not be more pleased to announce, on behalf of the entire BSF Board, that Marc Sernel—Barth Dad, Intellectual Property Attorney, Donor, Chemical Engineer, Chicago resident—has accepted our invitation to join the Barth Syndrome Foundation's Board of Directors.

Marc and his wife Tracy live with their three children just outside of Chicago, Illinois. Marc and Tracy have a three-year-old son with Barth syndrome and his perspective as a parent of a younger child will add a valuable voice to the BSF Board as we plan for the future. The Sernel family joined BSF in 2006 and attended their first Conference that year in Orlando. Marc recalls being very impressed with the professionalism and depth of the information and presentations, and of the BSF organization as a whole. The family returned along with Tracy's parents to attend the 2008 Conference in Clearwater and grew in their admiration for and appreciation of the effort that BSF was making on behalf of their son.

Marc earned a BS in Chemical Engineering from the University of Illinois in 1992 and then went on to graduate first in his class from Loyola University Chicago School of Law in 1997. His training may explain why Marc may have been the only parent in the room who fully understood Dr. Christie's lipid chemistry lesson during the Family Sessions at the 2008 Conference! He continued to leverage his interest in science and his law degree as a Partner at Kirkland & Ellis—one of the largest and most prestigious law firms in the country. Marc's specialty at Kirkland & Ellis is intellectual property where he concentrates on patent and other technology related litigation with a particular focus on chemical, pharmaceutical and biotechnology matters.

Marc's experience as the father of a young boy with Barth syndrome, his training, education and contacts will all make him a welcome addition to the Board. He and his family have been major donors to BSF in the past and look forward to building BSF's family and donor base in the Chicago area. In addition, Marc's natural interest in science and his familiarity with the pharmaceutical and biotechnology industries makes him a particularly valuable advisor and Board member as BSF pushes deeper and deeper into research and potential medical treatments for Barth syndrome.

I know I speak for every member of the Board of Directors in welcoming Marc to the Board and a position of leadership on behalf of the greater Barth community.



## Research Corner

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

### 2008 BSF Research Grant Program highlights clinically-driven ideas

The latest cycle of the BSF Research Grant Program marks the seventh anniversary of this important funding program. Two of the four awardees have not received funding from the BSF before. Below is a summary of the main focus of each individual grant with some thoughts of what value it will bring towards achieving our ultimate goal.



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

**“The role of tafazzin in mitochondrial protein import—implications for Barth syndrome”**

USD \$40,000 for 1 year

*\*Funding provided by BSF and BSFCa*

Using yeast as a model system, Dr. Greenberg will expand on her recent discovery of the synthetic lethality of tafazzin and Tom5 mutations. This discovery shows that there is a connection between the causative gene of Barth syndrome (BTHS), tafazzin, and at least one member of the mitochondrial protein import machinery, Tom5 (translocase of the outer membrane 5). This connection is made even more interesting by considering that the autosomal recessive disease called DCMA (dilated cardiomyopathy and ataxia) or Barth-like syndrome is caused by a mutation in the DnaJC19/TIM14 gene which is a member of the mitochondrial protein transport mechanism. The common symptoms between BTHS and DCMA (cardiomyopathy, neutropenia, 3-methylglutaconic aciduria, and growth delay) suggest a common biochemical mechanism. Dr. Greenberg will use suppressor gene analysis to find out which other gene(s) are connected with the tafazzin-Tom5 system by finding out what third mutation(s) allows the tafazzin-Tom5 double mutant to live (i.e. suppression). She

*(Cont'd on page 8)*

# Research Corner

(Cont'd from page 7)

will also treat the double mutant with different lipids/oils to determine if this chemical supplementation could also suppress the lethality. By understanding what aspects of the biochemical dysfunction caused by a tafazzin mutation cause what symptoms, one may be able to logically identify potential treatments. For example, can simply adding certain fatty acids to the diet be useful?



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

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



**Genevieve Sparagna, PhD**, Faculty Research Associate, University of Colorado at Boulder, Boulder, CO  
“**Fatty acid combinational therapy for Barth syndrome (BTHS) investigated using a rat model of heart failure**”  
USD \$40,000 for 2 years

Dr. Sparagna previously showed, with a genetic rat model of hypertension/heart failure (SHHF rat), that tafazzin gene expression and cardiolipin amounts decreased as heart failure became more acute. In this proposal she pursues her recent discovery that a diet supplemented with high linoleic safflower oil can increase survival and increase heart tetralinoleoyl cardiolipin levels in these same rats. The same diet supplement was used in some BTHS patients without noticeable effect, however the data are scarce. Dr. Sparagna believes that the expected benefits of linoleoyl supplementation may have been attenuated or reversed in humans by a biochemical perturbation that increased the production of an inflammation-associated fatty acid—arachidonic acid. In aim 1, Dr. Sparagna will

investigate whether sucrose in the diet of SHHF rats increases inflammation and whether linoleoyl acid supplementation can ameliorate this. She postulates that the presence of refined sugar in the diet (not in typical rat diets but certainly present in the human diet) makes a difference with regard to the cardiolipin and cardiac parameters. In aim 2, Dr. Sparagna will test whether adding fish oils to the linoleoyl diet can improve the cardiolipin and cardiac parameters, with (or without) refined sugars. She hypothesizes that by using fish oil to inhibit some of the enzymes that may lead to inflammation (inhibition of the delta 6 and the delta 5 desaturases of fatty acid elongation) a better cardiac outcome may be attainable in the SHHF rat. Obviously, the same treatment would be amenable to try in humans.



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

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

These 2008 grant recipients are testing ideas or measuring parameters that will lead to a better understanding and perhaps to a better treatment of BTHS individuals. All of the recipients are building on previous work performed in their laboratory or at the clinics of the BSF biennial conferences. During this seventh year of the BSF Research Grant Program the number of publications about BTHS continues to increase (*see graph on page 9*). Many of these publications can be associated with the grant funding and with the conferences that the BSF has sustained over the years. The BSF can take a large measure of satisfaction in knowing that they have made a difference to the scientific and medical advancement of BTHS research. Several previous BSF Research Grant recipients and others connected with our community (*see box on page 1*) have recently received NIH grants to study BTHS in more detail. The fact that we are seeing journals and government/private funding organizations recognize the value of this work validates our efforts. The BSF and I would like to thank all of the present and previous grant recipients and every other researcher/clinician in the BTHS community for accomplishing our goal of stimulating BTHS research.

(Cont'd on page 9)



(Cont'd from page 8)

## Barth Syndrome (BTHS) Research Paper Garners Widespread Attention

In the February, 2009 issue of the prestigious Proceedings of the National Academy of Sciences, USA, the laboratories of Mindong Ren and Michael Schlame at the New York University Langone Medical Center published an article which caused an unusual but justified degree of attention (*Proc Natl Acad Sci U S A*. 2009 Feb 17;106(7):2337-41). As you may know, Dr. Ren is a previous BSF Research Grant Recipient while Dr. Schlame is a member of BSF Scientific and Medical Advisory Board (see *BTHS researcher profile on page 10*). This paper describes the great progress made by using the fruit fly model of BTHS. As partly revealed at the 2008 BSF International Research Conference in Clearwater, Florida, not only does this animal model show interesting parallels to human BTHS, the researchers used the power of genetics to isolate genes that interact with the causative gene of BTHS, tafazzin. They discovered that mutations in a specific enzyme called calcium-independent phospholipase A2 can fix or suppress the symptoms of a fly with a total loss of tafazzin. In addition, the authors rigorously demonstrated that this phenomenon of suppressing the tafazzin fly mutant can be accomplished, in part, by treatment with a chemical compound (bromo-enol lactone) that inhibits the same phospholipase—a significant achievement which is directly related to drug discovery.

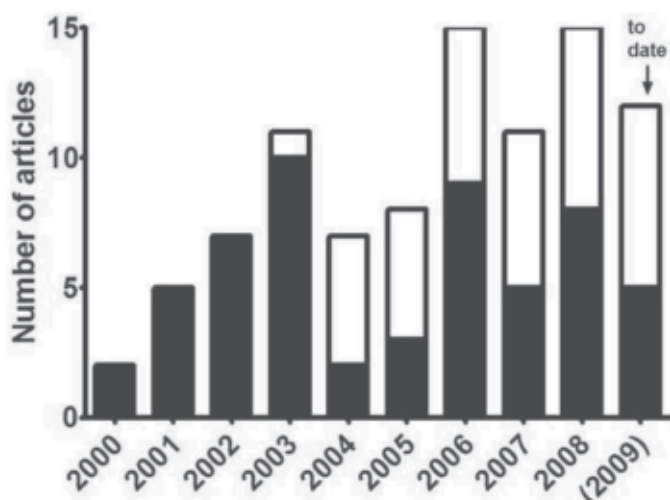
After this publication was issued, several internet-based information services picked up on the importance of the paper to the rare disease research community and of course, to the BSF. While it is reckless to predict the future of medical advancements, one can confidently conclude that the state of BTHS research and the search for a treatment is significantly better off with the extraordinary dedication and hard work of these researchers and their staff.

## The Mouse Model in Barth Syndrome Research

Some of the most important tools in finding new treatments for human disease are animal models of that human disease. BTHS research already has benefited tremendously from the creation of models of the disorder in yeast (*Saccharomyces cerevisiae*), fruit flies (*Drosophila melanogaster*) and zebrafish (*Danio rerio*), but the creation of a mammalian model has proven to be extremely difficult. Besides allowing for a better understanding of the details and mechanism of the disease, a mammalian model (often a mouse) may also allow for the testing of drugs or treatments to determine if they are effective. Several expert attempts utilizing various approaches to make a mouse model of BTHS have not been successful. These attempts involved trying to create a mouse in which the function of the gene that causes BTHS, called tafazzin, is completely “knocked out.” From the beginning of the BSF Research Grant Program the creation of such a “BTHS mouse” has been a high priority and has received specific donor support from the Annenberg Foundation and from the Paula and Woody Varner Fund.

Because these previous approaches did not seem to be working, in April 2008, the Barth Syndrome Foundation, Inc. commissioned the TaconicArtemis GmbH company to make a different sort of mouse model of BTHS—a tafazzin “knockdown” mouse. If successful, these animals would have the function of the relevant gene reduced (knocked down) but not completely eliminated (knocked out). This approach has great potential, and the first of these tafazzin “knockdown” mice are scheduled to be delivered to at least three laboratories in May, 2009 for detailed analyses. While researchers will take several months to measure how closely these knockdown mice will mimic the symptoms of human BTHS, I am glad to report the significant progress made in providing this extremely important scientific and drug-discovery research tool.

### Relevant PubMed Articles



Open bar portions correspond to BSF acknowledgement.

Note: There were only 11 publications in total before 2000.

**Publication year**  
(search terms: Barth syndrome, tafazzin)



# A Conversation with Dr. Michael Schlame

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



Michael Schlame, MD, Cell Biology & Anesthesiology, NYU School of Medicine

**Tell me about your background: Where were you born and raised? When did you get interested in science/medicine? What was your educational background?**

**Dr. Schlame:** I was born in 1958 in East Germany and during my teenage years I

became seriously interested in chemistry and mathematics so much that I had a laboratory in my home, much to my family's anxiety. After working in a laboratory involving lipids at a medical school close to my home, I decided to study medicine, almost by accident. At that time East Germany was not a good place to be a scientist, but being a clinician was different so I decided to enter medical school in the town of Magdeburg and focused on anesthesiology and intensive care. I performed my residency in East Berlin and developed an interest in lipids and pulmonary surfactants. Frustrated with the political system, I left for Hungary in 1988 to take a position with a biochemical institute. The political system in Hungary became undesirable so I escaped to Serbia by swimming across the Theiss River which borders Hungary and Serbia. From there I made my way to West Germany and worked in Munich on mitochondria and lipids for one year. In 1990, I made my way to San Diego and worked with Dr. Karl Hostetler at UCSD who was interested in cardiolipin. In 1992, I traveled to St. John's University in Queens, NY, and then I went to the University of Michigan in Ann Arbor where I met Dr. Miriam Greenberg. By 1994, I went back to Berlin to finish my training in anesthesiology. Soon afterwards I migrated back to New York to the Hospital for Special Surgery where I met with Dr. Tom Blank. By 2001, Dr. Blank moved to NYU where I joined him, and I have been at NYU ever since performing clinical duties and running a research laboratory.

**How did you get involved in Barth syndrome research?**

**Dr. Schlame:** Dr. Salvatore (Billi) DiMauro of Columbia University was a good friend of my boss, Dr. Tom Blank. I met Billi at a social function, and he knew about my interest in cardiolipin so he sent me numerous samples from individuals with mitochondrial diseases to see if there were any cardiolipin changes—none of the samples showed any abnormality. At some point Billi speculated that a relatively newly-defined disease called Barth syndrome, may have a defect in cardiolipin. When I tested the first sample in September of 2000, I immediately saw a cardiolipin difference—something that I had not seen with so many other samples from Billi.

This started my interest with Barth syndrome. I contacted Dr. Richard Kelley who put me in touch with Shelley Bowen. Dr. Blank gave me funds to travel to Boston and obtain some fresh blood samples of a Barth syndrome individual from which I performed the cardiolipin measurement on the platelet fraction. This fresh sample confirmed the cardiolipin abnormality, and then I realized that Barth syndrome and cardiolipin were closely connected.

**Your recent publication with Dr. Mindong Ren in the prestigious journal, Proceedings of the National Academy of Sciences, USA, has garnered a lot of attention. Could you give us your thoughts?**

**Dr. Schlame:** I really liked the concept of this line of investigation, which was really Mindong's idea. The fruit fly model of Barth syndrome did not provide everything that we expected, however the monolysocardiolipin/cardiolipin ratio was altered. While this was a successful experiment it is not the solution to our problems, but it gives us an idea of a direction.

**Where do you see your research going in the near future?**

**Dr. Schlame:** Understanding the mechanism of tafazzin—what does it really do in the mitochondria? A better understanding of what is going on in the mitochondria will be valuable.

**Where do you see Barth syndrome research going in the near future?**

**Dr. Schlame:** I hope to see a lot more mechanistic studies about tafazzin and what happens when it is dysfunctional. I expect that I will get a lot of competition in this area which is a good thing as it shows that progress has been made and will continue being made. I would like to see better designed clinical studies which will be difficult because there are so few patients. There is also a lack of good clinical guidelines to follow which is more important to this group in particular because the patients are so widely scattered. A physician treating a Barth syndrome individual is often alone with no other patients to compare with or to learn what to expect or prepare for.

**I know that you financially give to the BSF as an organization, in addition to your research work. Why?**

**Dr. Schlame:** If you feel strongly about something, and you can do something to help out, then you should do it. One may feel reluctant to give to your own organization, but if it is important then you should do it.



# BSF Southeast Family Outreach

By Lee Kugelmann, Merritt Island, FL

This summer we would like you to join us for the Southeast Family Outreach, June 26-28, 2009. The Outreach will be held at Stone Mountain Park, about thirty minutes from Atlanta, GA. Hotel accommodations have been made at the Marriott at Stone Mountain (<http://www.marriott.com/hotels/travel/atlsi-stonemountain-inn/>).

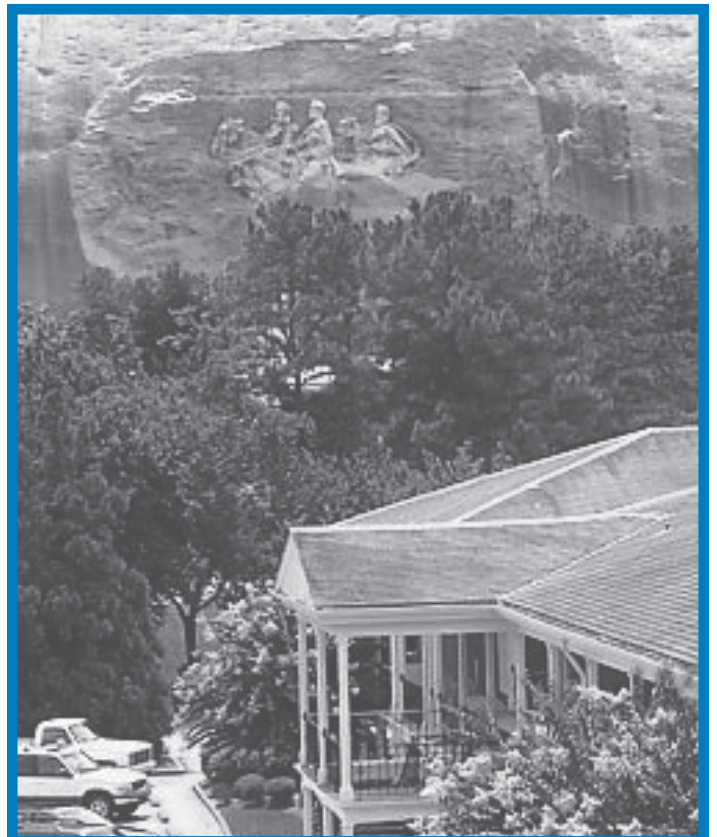
Schedule includes:

<b>Friday, June 26, 2009</b>	Arrive at Stone Mountain, GA
<b>1:00 PM - 4:15 PM</b>	<b>Educational Sessions</b> <b>Welcome</b> ~ Shelley Bowen, President, BSF <b>"The unpredictable nature in the symptoms of genetic metabolic diseases such as BTHS"</b> ~ Dr. Paul Fernhoff <b>"Genetic variants and disease causing mutations"</b> ~ Karlene Coleman, RN, MN <b>Update on BTHS Research</b> ~ Dr. Matt Toth, Science Director, BSF <b>Update on BSF Initiatives</b> ~ Linda Stundis, Executive Director, BSF
<b>5:30 PM</b>	Dinner Buffet
<b>Saturday, June 27, 2009</b>	<b>Stone Mountain Park activities</b> (Complimentary passes)
	Pizza by the pool
<b>Sunday, June 28, 2009</b>	Breakfast roundtable with Shelley Bowen, Linda Stundis, and Jan Kugelmann to discuss ideas for 2010 BSF International Conference

Everyone involved is very excited about this Outreach. We hope that many of you will be able to attend and share this experience with us. If you are able to attend, please contact Shelley Bowen ([sbowen@barthsyndrome.org](mailto:sbowen@barthsyndrome.org)).



Join us at the Marriott Stone Mountain Inn for BSF's Southeast Family Outreach ~ June 26-28, 2009.



# Barth Syndrome Foundation

## A Strong Year in a Difficult Time

*By Stephen McCurdy, Chairman, Barth Syndrome Foundation*

The Barth community has certainly had more than its share of unsettling news from the beginning of 2008 to date, led by the loss of three sons, one father, and a major benefactor. One's sense of personal loss could be easily mirrored and magnified by the daily paper and the nightly TV news stories of savings and jobs lost, and of instability in institutions we thought were solid and reliable. Optimism seems in short supply in the world today, and the future increasingly opaque.

It could be overwhelming... but for the members of the Barth community, it is not.

Despite the sadness of the present and the extraordinary challenges we each face every day, there is a resiliency and an unexpected strength to this group. Five parents of Barth children, three of whom had lost children of their own to this disorder, showed up to support the Telles family during the funeral of their son, Michael, last month. They represented us all. Michelle Telles has since led one of the most personal and yet educational discussions on the BSF family listserv we have seen to date to help other families better care for their own sons. The number of families joining in listserv discussions is greater than ever, and many of them are speaking up for the first time. We find our strength in each other.

For the families who struggled with Barth syndrome before 2000, many of whom may never have received a definitive diagnosis of the genetic "error" that often took their children, the existence of the Barth Syndrome Foundation and the community that has grown around it is a miracle. And despite, indeed, perhaps because of the threat that Barth syndrome still represents to the lives of our families, the Barth Syndrome Foundation is, in many ways, stronger than ever.

We clearly share a common vision of a world without Barth syndrome, and just as clearly we will not give up this quest until it has been achieved. When you think of it, this is not at all the picture of a group of individuals facing the future alone, without hope or direction. We all understand that our future will be difficult and that there will be losses... unrecoverable losses. But we are collectively committed to our path together because we know that it is the only one we can take. We know that our actions will make a meaningful difference. They already have.

In every year, we take a few more steps in the direction of our goals. 2008 was another such year.

- We held our Fourth International Barth Syndrome Science, Medical and Family Conference featuring two days of clinics where critically important data were gathered from 29 affected boys and young men for the

Barth Registry and Repository, followed by dual tracks of presentations and symposia for and among scientists/clinicians and families. These meetings are critically important to the advancement of cooperation, science, and understanding among all three key groups.

- We awarded nine new research grants for over \$333,000 in early 2008 and another four exceeding \$143,000 in early 2009. Three scientists associated with BSF have recently been awarded major NIH research grants, based in part on work that has been funded or encouraged by BSF. Detailed descriptions of all of these awards can be found in this Journal.
- After numerous efforts and thousands of dollars of research grants by BSF, Matt Toth, our Director of Science, with the help of Taconic Artemis, has succeeded in reaching a major milestone toward the creation of a Barth mouse—a critically important animal model that we hope will help us better understand Barth syndrome and lead us to a cure.
- We welcomed two new Board members, Randy Buddemeyer and Marc Sernel. Randy brings his business acumen and now serves as BSF's Treasurer, and Marc is the Corporate Secretary and will lend his considerable legal and scientific training to our planning and decision making.
- Awareness of Barth syndrome, its symptoms and BSF was advanced by appearances on the TODAY Show and in PARADE Magazine's on-line edition, as well as numerous fund-raising efforts.
- Through Linda Stundis' efforts, BSF became fully certified by the Better Business Bureau, adding their endorsement to that of the National Health Council and enhancing our credibility to prospective donors.

### Financial Condition

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

*(Cont'd on page 13)*

(Cont'd from page 12)

		The Barth Syndrome Foundation, Inc. Statement of Activities For the Years Ended December 31		
		2008	2007	2006
<b>Public Support &amp; Revenue</b>				
	Contributions	\$ 727,957	\$ 674,457	\$ 1,018,888
	Other	\$ 133,788	\$ 116,505	\$ 66,816
	<b>Total Support &amp; Revenue</b>	<b>\$ 861,745</b>	<b>\$ 790,962</b>	<b>\$ 1,085,704</b>
<b>Expenses</b>				
	Program Services	\$ 894,904	\$ 596,095	\$ 550,838
	Management & General	\$ 160,139	\$ 81,864	\$ 98,875
	Fund Raising	\$ 11,582	\$ 12,372	\$ 4,115
	<b>Total Expenses</b>	<b>\$ 1,066,625</b>	<b>\$ 690,331</b>	<b>\$ 653,828</b>
<b>Change in Net Assets</b>		( 204,880)	\$ 100,631	\$ 431,876
<b>Net Assets - Beginning of Period</b>		<b>\$ 2,429,765</b>	<b>\$ 2,329,154</b>	<b>\$ 1,897,278</b>
<b>Net Assets - End of Period</b>		<b>\$ 2,224,905</b>	<b>\$ 2,429,785</b>	<b>\$ 2,329,154</b>

		The Barth Syndrome Foundation, Inc. Statement of Financial Position At December 31		
		2008	2007	2006
<b>Assets</b>				
	Current Assets	\$ 2,375,329	\$ 2,613,769	\$ 2,460,331
	Other Assets	--	--	--
	<b>Total Assets</b>	<b>\$ 2,375,329</b>	<b>\$ 2,613,769</b>	<b>\$ 2,460,331</b>
<b>Liabilities</b>				
		\$ 150,424	\$ 183,984	\$ 131,177
<b>Net Assets</b>				
	Unrestricted	\$ 1,486,721	\$ 1,993,659	\$ 1,939,939
	Temporarily Restricted	\$ 738,184	\$ 436,126	\$ 389,215
	<b>Total Net Assets</b>	<b>\$ 2,224,905</b>	<b>\$ 2,429,785</b>	<b>\$ 2,329,154</b>
<b>Total Liabilities &amp; Net Assets</b>		<b>\$ 2,375,329</b>	<b>\$ 2,613,769</b>	<b>\$ 2,460,331</b>

As the year progressed, it became apparent that BSF, along with most other charities, would suffer a significant reduction in contributions, both in number and in size of average donation. We typically receive the majority of our donations in the last quarter of the year, even though our programs are funded year round. As markets sank, unemployment rose and confidence diminished, so too our donations fell. But for the generous donation of Mrs. Annenberg, BSF would have suffered a much more severe deficit in 2008.

In 2009, we know that we face a serious fund-raising challenge. We have economized on our programs and administrative budgets everywhere we can without doing long-term damage to our programs or our future. Indeed, reduced investments in research in 2009 reflected a decrease in research proposals received. We funded all of the proposals reviewed and recommended by our Scientific and Medical Advisory Board. Our staff has been granted neither bonuses nor an increase in compensation for 2009. 2009 is not a Conference year for BSF, but we are certainly planning and looking forward to another successful Conference in Panama City, Florida in July of 2010.

The net assets on our balance sheet (essentially, the funds we have in the bank or in CDs) can sustain us for a while, but additional fund-raising efforts are critical if we are to continue the great progress already made by our programs. We appreciate the steadfast loyalty of our long time donors and hope that they can sustain, even increase, their gifts to BSF. And we will need to continue to search for new donors who can share our vision and help to insure our success. Most of all, we need to ask every member of our community to step up and become not just a contributor, but a fund raiser... an advocate for and proponent of BSF. Linda Stundis and the entire Board are working ever harder to address this crucial challenge, and we need your help!

(Cont'd on page 14)

## Fund-Raising

For 2008, we saw many repeat fund-raisers and welcomed several new intrepid sponsors as well. We thank you very much and hope everyone will lead their own fund-raising effort in 2009... clearly we need you!



Sue Wilkins raised donations for the Paula and Woody Varner Fund (that helps support our Science and Medicine programs) by writing letters to her family's friends and her father's associates. Sue has written again already in 2009 and the gifts continue to come in!

The McCurdys also sent their annual letter in late 2008 and are committed to fund-raising again in 2009.

Coach Gary Rodbell and his growing team of triathletes led an electronic solicitation and introduced Barth syndrome to a large number of new donors in 2008. They will be racing again in the fall and have already begun to train for their race and their fund-raising! (1st photo)



Jessica Wiederspan, another Wilkins family athlete, participated in a 10K race at the University of Michigan to raise money for BSF. (2nd photo)

John and Liz Higgins are veteran bowlers and fund-raisers and did it again in 2008. Family and friends, including the Dunns and Lynda Sedefian, gathered to bowl and contribute in Warwick, NJ. (3rd photo)



Randy Buddemeyer and his friend, Tim Rivers, held the CB Richard Ellis Annual Golf Tournament for BSF and JDRF. They have increased their donation from the tournament to BSF every year for three years. (4th photo)

Tracy Brody used the 2008 Conference and her wonderful quilt-making skills to increase awareness and raise contributions for BSF through a quilt raffle. (5th photo)

Several loyal and concerned contributors supported the BSF Conference with specific donations, including the Barth Syndrome Foundation of Canada, several of our families and members of our own SMAB.

Many friends and families were motivated to make a donation to BSF in memory of a loved one or in honor of a birthday or anniversary.



We continue to have a growing number of donors who contribute monthly on-line via Facebook or Network for Good.

And, of course, Mrs. Annenberg made a gift to BSF shortly before she passed away... a final and especially poignant gift from an old and loyal friend.

If you helped us raise donations in 2008, we need you to do so again and increase your targets. We cannot count on a gift like that from Mrs. Annenberg to save us in 2009. We must count on each of you... friends, families, physicians, scientists and all those whose hearts we have touched in the past to help us stay the course. It's up to you.



***“If you feel strongly about something, and you can do something to help out, then you should do it. One may feel reluctant to give to your own organization, but if it is important then you should do it.”***

*~ Michael Schlame, MD*

# 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.

	Science & Medicine	Family
July 26, 2009		Family Registration
July 27-28, 2009	Clinics (doctors/physicians involved in Barth syndrome research)	Barth Syndrome Clinics
July 28, 2009	Doctor/Physician Registration	
July 29-30, 2009	Scientific & Medical Sessions	Family / BTHS Individual / Sibling Sessions
July 31, 2009	SMAB Meeting	Closing Ceremony

Mark your  
calendars **NOW!**



# Awareness of Barth Syndrome is Growing Exponentially

There has been a significant increase in BTHS related peer-reviewed journal articles published. To date, there have been 37 articles published with the support of BSF and/or BSF affiliate funding.\* Listed below are the articles added to BSF's library since November 2008:

- Schug ZY, Gottlieb E. **Cardiolipin acts as a mitochondrial signalling platform to launch apoptosis.** Biochim Biophys Acta. 2009 May 15. [Epub ahead of print].
- Claypool SM. **Cardiolipin, a critical determinant of mitochondrial carrier protein assembly and function.** Biochim Biophys Acta. 2009 May 5. [Epub ahead of print]
- Schlame M, Ren M. **The role of cardiolipin in the structural organization of mitochondrial membranes.** Biochim Biophys Acta. 2009 May 1. [Epub ahead of print]\*
- Schlattner U, Tokarska-Schlattner M, Ramirez S, Brückner A, Kay L, Polge C, Eband RF, Lee RM, Lacombe ML, Eband RM. **Mitochondrial kinases and their molecular interaction with cardiolipin.** Biochim Biophys Acta. 2009 Apr 29. [Epub ahead of print]\*
- Rivers A, Slayton WB. **Congenital cytopenias and bone marrow failure syndromes.** Semin Perinatol. 2009 Feb;33(1):20-8. Review.
- Lotstein DS, Ghandour R, Cash A, McGuire E, Strickland B, Newacheck P. **Planning for health care transitions: results from the 2005-2006 National Survey of Children With Special Health Care Needs.** Pediatrics. 2009 Jan;123(1):e145-52.
- Zhou J, Zhong Q, Li G, Greenberg ML. **Loss of Cardiolipin Leads to Longevity Defects that are Alleviated by Alterations in Stress Response Signaling.** J Biol Chem. 2009 Apr 28. [Epub ahead of print]\*
- Singh HR, Yang Z, Siddiqui S, Peña LS, Westerfield BH, Fan Y, Towbin JA, Vatta M. **A novel Alu-mediated Xq28 microdeletion ablates TAZ and partially deletes DNL1L in a patient with Barth syndrome.** Am J Med Genet A. 2009 Apr 24;149A(5):1082-1085. [Epub ahead of print]
- Mileykovskaya E, Dowhan W. **Cardiolipin Membrane Domains in Prokaryotes and Eukaryotes.** Biochim Biophys Acta. 2009 Apr 13. [Epub ahead of print]
- Paradies G, Petrosillo G, Paradies V, Ruggiero FM. **Role of cardiolipin peroxidation and Ca(2+) in mitochondrial dysfunction and disease.** Cell Calcium. 2009 Apr 13. [Epub ahead of print]
- Sparagna GC, Lesnefsky EJ. **Cardiolipin Remodeling in the Heart.** J Cardiovasc Pharmacol. 2009 Mar 7.\*
- Bachou T, Giannakopoulos A, Trapali C, Vazeou A, Kattamis A. **A novel mutation in the G4.5 (TAZ) gene in a Greek patient with Barth syndrome.** Blood Cells Mol Dis. 2009 Mar 2.
- Beranek A, Rechberger G, Knauer H, Wolinski H, Kohlwein SD, Leber R. **Identification of a cardiolipin-specific phospholipase encoded by the gene CLD1 (YGR110W) in yeast.** J Biol Chem. 2009 Feb 25.
- Gohil VM, Greenberg ML. **Mitochondrial membrane biogenesis: phospholipids and proteins go hand in hand.** J Cell Biol. 2009 Feb 23;184(4):469-72.
- Roig T, Martinez-Seara H, Munck N, Karttunen M, Vattulainen I. **Role of Cardiolipins in the Inner Mitochondrial Membrane: Insight Gained through Atom-Scale Simulations.** J Phys Chem B. 2009 Feb 19.
- Finsterer J. **Cardiogenetics, Neurogenetics, and Pathogenetics of Left Ventricular Hypertrabeculation/Noncompaction.** Pediatr Cardiol. 2009 Jan 29.
- Houtkooper RH, Rodenburg RJ, Thiels C, van Lenthe H, Stet F, Poll-The BT, Stone JE, Steward CG, Wanders RJ, Smeitink J, Kulik W, Vaz FM. **Cardiolipin and monolysocardiolipin analysis in fibroblasts, lymphocytes and tissues using high-performance liquid chromatography-mass spectrometry as a diagnostic test for Barth syndrome.** Anal Biochem. 2009 Apr 15;387(2):230-7. Epub 2009 Jan 31.\*
- Schlame M. **Formation of molecular species of mitochondrial cardiolipin. 2. A mathematical model of pattern formation by phospholipid transacylation.** Biochim Biophys Acta. 2009 Apr;1791(4):321-5. Epub 2009 Jan 31.
- Malhotra A, Xu Y, Ren M, Schlame M. **Formation of molecular species of mitochondrial cardiolipin. A novel transacylation mechanism to shuttle fatty acids between sn-1 and sn-2 positions of multiple phospholipid species.** Biochim Biophys Acta. 2009 Apr;1791(4):314-20. Epub 2009 Jan 21.\*
- Wittig I, Schägger H. **Supramolecular organization of ATP synthas & respiratory chain in mito membranes.** Biochim Biophys Acta. 2009 Jan 8.
- Wendel AA, Lewin TM, Coleman RA. **Glycerol-3-phosphate acyltransferases: Rate limiting enzymes of triacylglycerol biosynthesis.** Biochim Biophys Acta. 2008 Nov 7.
- Malhotra A, Edelman-Novemsky I, Xu Y, Plesken H, Ma J, Schlame M, Ren M. **Role of calcium-independent phospholipase A2 in the pathogenesis of Barth syndrome.** Proc Natl Acad Sci U S A. 2009 Jan 21.\*
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To view the complete bibliography on Barth syndrome, please visit [www.barthsyndrome.org](http://www.barthsyndrome.org).

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## NIH Research Initiatives Relevant to Barth Syndrome

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.

### Application of Metabolomics for Translational and Biological Research (R01)

Program Announcement (PA) Number: PA-07-301 (and the R21 version for pilot/exploratory projects: PA-07-302)  
Letters of Intent Receipt Date(s): N/A  
Expiration Date: January 3, 2010 (now January 8, 2010 per [NOT-OD-07-093](http://grants.nih.gov/grants/guide/pa-files/PA-07-093.html))<http://grants.nih.gov/grants/guide/pa-files/PA-07-301.html>

**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.

### Chronic Illness Self-Management in Children and Adolescents (R01)

Program Announcement (PA) Number: 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)  
Letters of Intent Receipt Date(s): N/A  
Expiration Date: January 3, 2010 (now January 8, 2010 per [NOT-OD-07-093](http://grants.nih.gov/grants/guide/pa-files/PA-07-093.html))<http://grants.nih.gov/grants/guide/pa-files/PA-07-097.html>

**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.

### Diet Composition and Energy Balance (R01)

Program Announcement (PA) Number: PA-07-218  
Letters of Intent Receipt Date(s): N/A  
Expiration Date: March 6, 2010  
<http://grants.nih.gov/grants/guide/pa-files/pa-07-218.html>

**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.

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

Program Announcement (PAR) Number: PAR-09-031  
Application Receipt/Submission Date(s): October 24, 2011  
<http://grants.nih.gov/grants/guide/pa-files/PAR-09-031.html>

**Purpose:** The Division of Musculoskeletal Diseases of the NIAMS supports fundamental research in bone, muscle and connective tissue biology as well as research aimed at improving the diagnosis, treatment, and prevention of diseases and injuries of the musculoskeletal system and its component tissues. Key public health problems addressed by this research include osteoporosis, osteoarthritis, orthopaedic disorders and injuries, including sports medicine and regenerative medicine and the muscular dystrophies.

This is an R03 grant program which is designed to help young investigators.



# Barth Syndrome Trust

## *Travelling Hopefully*

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



*A well earned rest after chasing cheetahs and lions all morning!*

*(April 2009)*

At our first volunteer workshop, back in 2005, one of our dads asked Shelley Bowen, “When will there be a cure?” Shelley always thinks deeply before she speaks and, after a short pause, responded gently, “I’m not sure there will be one in my lifetime.” A stunned silence filled the room. Here we all were, fired up about making a difference and one of the founder members, visiting from the States had, in one sentence, killed our hopes. “So what are we doing here today then?” he asked.

I can’t remember the answer. But I do remember that we sat down and worked very hard for two days scoping out what we were going to accomplish. And so, it seemed that our hopes were not so easily destroyed. We had come to realise that the fact that there might not be a quick fix to this problem did not mean that we should not continue in our quest to fix the problem. Our mindset had to change.

We live in a fast changing and fast paced world. We’re used to quick action. The latest widescreen TV. Fast food. Busy schedules.

We see something we want and we do not hesitate to reach out and grab it.

A few days ago, my family had the great privilege of being on a safari in southern Africa. To be the only people out in an open topped Landrover as the sun comes up and to see the land spread out before you in all directions as far as you can see, is a chance to breathe, recharge and once again to feel reconnected to the energy that nature provides. But our peace was soon shattered by a plaintive voice from the back of the Landrover – our ten year old son asking, “Where are the cheetahs, Mom? We haven’t seen any animals yet and we’ve been out here for a while now.”

And when we are out there in the wilderness, we need to hurry up and wait. We need to be patient and settle into the ancient rhythms of the bushveld. And this is no passive exercise; instead it is an active waiting, you are constantly driving, looking, searching and scanning the distance.

We were trying to find the cheetahs that had been spotted the previous day. We had some idea of where to look but they are hard to see in the dappled morning light. And then, suddenly, we turned a corner and there they were—four beautiful animals, on a hunt. A young zebra foal up on the nearby hill was their intended target. We had expected to stop the Landrover and watch them. Instead, we were following the big cats as they were chasing the zebra, marvelling at their grace, speed and agility whilst hoping that today, the zebra foal would escape.

We had set out to find the cheetahs and we had succeeded. But we had not known where our journey was to take us that morning. As the cheetahs were just about to spring on the zebra, everything suddenly changed. In a split second the cheetahs changed direction and scattered as a pride of seven lions burst out from our right, aimed straight towards our vehicle, intent on either killing or at the very least chasing off the cheetahs from their territory. Often you drive for hours to see lions asleep in the shade of a tree. This, instead, was a unique chance to see these magnificent animals in action and to witness their power, size and strength. It was as exciting as it was unplanned.

I remember once talking to Shelley and saying that our Barth journey is no 100 metre sprint; instead it is a gruelling marathon through the harshest of landscapes. But, as I think back to our stay in the African bushveld, I think I might switch gears a little and change my perspective for a while. Perhaps our journey is like our safari—we are in a beautiful and often savage land. Thanks to our dedicated scientists and doctors, we have some idea of where to find what we’re looking for. But there are no tarred highways here and we cannot be sure where we will go in search of our answers. And yes, along the way, we mustn’t forget to stop for a while and take time to enjoy our drinks and snacks as we watch the beautiful African sunset.



# Barth Syndrome Trust

## *Making the Future Today*

This past year has been a busy and productive year and it has been gratifying to see some major projects into completion. Our trustees, volunteers and family members have all worked very hard to ensure the growth and sustainability of the organisation. Most importantly, we have continued to make a difference in the lives of boys affected by Barth syndrome. As the mother of a child who has Barth syndrome and as the Chairperson of the Trust, I would like to extend my deepest thanks to everyone who has contributed to our ongoing success. We are grateful to the Barth Syndrome Foundation, Barth Syndrome Foundation of Canada and the Barth Trust of South Africa for their unstinting help and advice.

### Getting the Message Across

#### Translations

Awareness of Barth syndrome is progressing in Europe as more information is translated into European languages by dedicated BSF and BST volunteers.

#### New diagnostic test

Key clinicians are being informed about the new bloodspot test available for a quick and reliable diagnosis of Barth syndrome.

#### Family Route Map

This booklet produced with the Genetic Interest Group provides signposting to appropriate information and services in the UK. It was distributed to affected families, genetic centres and healthcare professionals in 2008.

#### Rare Disease UK launched November 2008

The Barth Syndrome Trust is a member of Rare Disease UK, a joint initiative of the Genetic Interest Group and others. It will help ensure the efficient use of scarce expertise, and the targeted use of health care resources to maximise the benefits for all patients and families affected by rare disease across the UK.

#### Children's Heart Federation

We believe very strongly in cooperation with like-minded groups and increasing our impact by pooling resources. Michaela Damini has continued working with the Children's Heart Federation (CHF) in her role as Council Member. We would also like to thank the CHF for sponsoring one of our families to attend a 'Christmas Spectacular Weekend' at the Alton Towers Resort Hotel.



*(L-R): Gill and Jack enjoy the Christmas Spectacular Weekend thanks to Children's Heart Federation.*

*(December 2008)*



*(L-R): At the Bristol Clinic - Will, Oliver, Eden, Nick, Ellie, Matthew, Alex, Jack, Michaela Damini and Dillon.*

*(December 2008)*

*(Cont'd on page 20)*

# Making the Future Today

(Cont'd from page 19)

## Website

Together with the BSF, we have been translating more of our international and local websites into various languages. Through our websites [www.barthsyndrome.org.uk](http://www.barthsyndrome.org.uk) and [www.barthsyndrome.org](http://www.barthsyndrome.org), we have attracted new families from Europe and UK and have also received requests for information from interested professionals in the healthcare field.



*Dillon and friend present a posy to the Princess Royal. (Photo courtesy of the Chesterfield Royal Hospital)*

*(March 2009)*

## Family Services

### UK Family Gathering

On the 13th December, the day after the clinic, our families gathered for brunch. This was another wonderful opportunity for families to relax together, exchange notes and ask questions arising from the clinic. One young man who attended without his family for the first time enthused, "The clinic is run very well. Also I like to see everyone and catch up. I think that it is important, now that I am getting older, to keep up to date with what is going on with the Trust."

We were pleased to welcome two more grandmothers to the Clinic and Gathering in 2008. They were very impressed with the whole weekend and learned a lot.

### New Family Brochure

Many of our families have spoken of the bewildering time before and just after diagnosis when they were overwhelmed by information and fear. A brochure was created for newly diagnosed families in 2008 and is now in use.

### New Hospital Emergency Information Pack

We helped families to create an Emergency Pack which has all the necessary information about the syndrome as well as an individualised Care Plan for each child. This distinctive pack can be kept somewhere safe to be located quickly for emergency visits to the hospital.

### Meeting the Princess Royal

One of our boys, three-year-old Dillon, was chosen with another young patient to present a posy to the Her Royal Highness at Chesterfield Royal Hospital. The Princess was visiting The Den, a play and development centre for pre-school children with complex health care and special needs at the hospital. We were all so proud of our little prince, Dillon.

## Science and Medicine

### Dedicated Barth Clinic

The highlight of our year, our annual clinic with the Bristol Royal Hospital for Children was held on 12th December 2008. Families from all over the UK attended. Affected children were evaluated by experts and parents had the opportunity for one-to-one meetings with the doctors as well as an open group discussion.

We hope to improve on the clinic year by year so that it becomes even more effective for the families who attend and for all those who are affected by Barth syndrome. Parents are already looking forward to the next clinic on 18th September. It was good to have Dr Arnie Majumdar, muscle specialist, with us for the first time. We are indebted to Dr Colin Steward, Dr Newbury-Ecob, Dr Tsai-Goodman and the team for all that they do.

*(Cont'd on page 21)*



*Families, medical staff and helpers at the Bristol Clinic.*

*(December 2008)*

(Cont'd from page 20)

We couldn't have managed without Lisa Gilmour and volunteers from her church who kept the children entertained all day in between their tests and during group discussions.

### **Barth Syndrome Medical Database & Biorepository**

Patients were also enrolled into the International Barth Syndrome Medical Database and Biobank with medical records and samples collected during the clinic.

Dr Poll-Thé is doing the final medical checks for the Dutch families. Once completed, the Dutch patients' medical background information will be submitted to the medical database.



*Glenna Stewart, outgoing ladies' captain, Weybrook Park Golf Club, Basingstoke presents a cheque to Greg Manton, BST. (April 2009)*

### **Fundraising**

We would like to thank all our donors and fundraisers for their generosity. Please see the list at the end of this Journal, where we have tried to acknowledge all those who helped since January 2008.

Our first major donation in 2008 was £1000 from the Freemasons' Grand Charity and a number of other large donations were received throughout 2008 to present from our families and friends in UK, Europe, Mauritius and Swaziland. Many of these were reported in the last newsletter.

In the current economic climate an important source of income continues to be grassroots fundraising. Our fundraisers have been very busy since the last newsletter. Here are some of their fundraising events:

- A group of brave 13 year-old carol singers raised £105.
- BST and Basingstoke Table Tennis League held a joint Quiz raising £235 for us despite deep snow and a bitterly cold night. Thanks to George White for compiling and presenting the quiz.
- Heather and Richard Oram's now traditional Fun Quiz in Overton Methodist Hall attracted a very generous capacity crowd on 7th March raising £500. Thank you to all those who rallied round to help and to the Methodists for the use of their hall and a donation of £100.
- The Ladies of the Weybrook Park Golf Club raised an amazing £1,650 during the captaincy of Glenna Stewart.
- The winning team at the 20th March Basingstoke and Districts Tennis League Quiz nominated BST to receive the profits and the League gave the proceeds of the raffle, altogether £300.
- Barth parents, Sarah Bull and her sister Tracy Woodward entertained another generous crowd at an evening of fundraising, awareness and fun, ending with a disco. The £2,645 raised was shared between BST and the Great Ormond Street Hearts for Kids fund.
- During a sponsored hair shave at the Fox and Hounds in Denmead, customers parted with £200 in addition to the amount already donated via the collecting box there. A party in March 2008 raised £450.
- Leigh McNally, sponsored in the Bristol half-marathon, collected £225.
- Lyn's persuasive telephone manner led to fundraising events hosted by Richard Brewer and the Masons which raised £1,022 for BST.
- Static collecting boxes raised a total of £1,745 in 2008.
- Supporters in Hampshire and Bristol have raised funds in a variety of other ventures: such as raffles, tuck shops at work and sale of goods.

(Cont'd on page 22)

# Making the Future Today

(Cont'd from page 21)

## Volunteers

### Translation

Thank you to all the volunteers who have been translating our information into several European languages. An appeal in Europe at the end of 2008 resulted in more offers of help with this enormous ongoing task.



Volunteer Workshop ~ February 2009

### Workshops

A meeting of volunteers at the end of 2008 focused attention on a new phase of activity and grassroots fundraising. At a workshop in February 2009 we discussed the future of the Clinic and raising awareness. Fundraisers thought of schemes for these difficult times, while families finalised the new brochure. We enjoyed seeing each other again and the Hampshire volunteers appreciated the efforts made by families to come from as far as Wales, the West Country and Derbyshire. Follow-up activities continue.

### Volunteer Policies and Handbook

This multi-purpose document has now been issued to each volunteer attending workshops. It will be updated regularly.

### A New Trustee

The Board of Trustees are thrilled to welcome Sonja Schlapak, mother of a two year old boy who has Barth syndrome, to the

Board. Sonja has been raising awareness in Germany and has helped with translations. She has also been able to assist with family services in Germany.

It was with regret that the Trustees have accepted the resignation from the Board of Sarah Bull, because of family pressures. We thank Sarah for her valuable contribution to the Board, with her practical approach, her knowledge of Family Services and her insight to the needs of young families. Sarah is still very much involved with the Trust in other areas.

## What do we plan to achieve in 2009

- Annual UK Clinic and Gathering in Bristol on 18th-19th September 2009.
- Mailings to genetic centres.
- Posters in hospitals throughout the United Kingdom.
- Enrolment of Dutch speaking patients into the Barth Syndrome International Medical Database and Biobank.
- We will actively seek partners (through grant making organisations and individual funders and fundraisers) in order to achieve our stated objectives.
- Improve the welcoming pack of information for new families.
- Continue translating our literature into European languages.

## Receipts and Payments Accounts

	31 Dec 2008	31 Dec 2007
Receipts	£13,825	£19,028
Payments	£ 8,482	£32,662
Net	£ 5,342	(£13,594)
Cash funds year end	£42,515	£37,800

# Partners in Profitable Persuasion



*Sarah and Dave Bull and Family. Their two younger sons have Barth syndrome.*

*(May 2008)*

Dave and Sarah Bull are inspirational. They have two sons and a nephew with Barth syndrome, which perhaps should have dampened their spirit and enthusiasm. It hasn't, quite the opposite. The catalogue of activities Sarah and Dave have organised or taken part in to raise much needed funds for BST seems endless, like their energy.

Sarah's main fundraising started with a sponsored head shave for over £5000. The close shave made no difference to her beauty. She was still as radiant as ever.

Then Dave ran the Bristol half marathon two years running, raising another £2000. This was a tremendous effort for one who is not a natural athlete, but he wanted to identify with the fatigue his sons feel every day of their lives. Dave then placed collecting boxes everywhere possible around their neighbourhood, to soak up loose change, over £3600 in two years. Dave's letter to shops and pubs contains the particularly moving sentence "... we have a lifetime to live with this, so if it is not possible for you to help now, please keep us in mind for the future."

In addition to the major fundraising there has been a steady flow of cheques including: money in lieu of Christening presents for their children, a donation from a Bingo win, small change from Birth of Barth month, to name but a few.

Time and again Sarah and Dave get people to open their hearts and their wallets. They appeal to, cajole or otherwise persuade friends and extended families to give money regularly. Dave's skill seems to be inherited from his Mum, Lyn who has been the inspiration behind a number of large donations organised by family members. Lyn's persuasive telephone manner led to fundraising events hosted by Richard Brewer and the Masons which raised £1,022 for BST. Further efforts from the Bull family have produced large donations from Sun Precision Engineering and Woodspring Masons.

Sarah's sister, Tracy Woodward, who has a son with Barth syndrome, is another partner in profitable persuasion. Sarah and Tracy at an evening of bingo, raffles, auction and dancing raised £2,645 for two causes dear to them, Great Ormond Street Hospital Hearts for Kids and BST. They have another major fundraiser planned for 31st May with the aid of another wonderful supporter, Dave Baber: a Sunday roast and auction of donated items at a pub. Dave Baber said that just hearing the sisters talking about Barth syndrome was all the inspiration he needed.

In addition to the fundraising, Sarah and Dave are active volunteers of BST. They are called upon to help with arrangements whenever the families gather for the Barth Clinic. Both Sarah and Dave are also on the Family Services Team. Sarah was also a Trustee before family pressures caused her to resign. Their three sons and a very lively daughter keep them very busy.

Sarah, Dave and their extended family and friends live in Bristol, an old city with a long mercantile and seafaring tradition. Some of the city's old spirit of enterprise and adventure is still very much alive in this family. Thank you, Dave and Sarah and the people of Bristol.



## SAVE the DATE

**Friday 18th September 2009 ~ Barth Clinic (Bristol, England)**

**Saturday 19th September 2009 ~ Family Gathering**

# Barth Syndrome Foundation of Canada

## *Growth through Volunteerism*

By Lynn Elwood, President, Barth Syndrome Foundation of Canada



*Canadian volunteers knit Barth sweaters for bears. The Barth awareness bears are given to children and carried by anyone who is willing to share awareness.*

Each year as we look back at our accomplishments and our learning experiences, we are once again amazed at the progress that has been made through the strength of our volunteers. Again we have grown the base of active volunteers who work with us, and as always they bring new and fresh ideas that help in many ways. Our existing base of volunteers including the board and executive continue to provide ongoing support to the daily operations and to the running of BSFCa programs.

There are several articles reflecting our accomplishments in the last few months. Please take the time to review all of the Canadian pages for an update on some of the program activities.

### 2008 Financial Summary

The 2008 year was a strong one in the area of finance. We were successful in spending funds on programs that bring value to our membership. In past years we raised funds and were able to put some away for future larger expenditures. 2008 marked the year that we used some of those funds to further programs such as Scientific and Medicine, Family Services, Awareness and Charity Support.

The financial summary as presented in our audited financial statements is as follows:

Our 2009 financial planning has taken the current economic conditions into consideration and both plans and actual expenditures are reviewed regularly by the board. We have re-worked the budget within 2009 to reflect more conservative expectations, and will continue to watch the budget compared to actual expenditures throughout the year and adjust accordingly.

Year ending December 31, 2008		
<b>Opening Balance</b>		<b>\$73,456</b>
Revenue	\$73,870	
Expenses	\$22,614	
Excess (Deficiency) of revenue over expenses before funding	\$51,256	
Research grant funding	\$58,324	
Excess (Deficiency) of Revenue over expenses and funding		\$ (7,068)
<b>Closing Balance</b>		<b>\$66,388</b>

### Science & Medicine – Funding of Scientific Grants

This marked our 4th year of funding scientific grants. In the 2008 budget year, scientific grant funding comprised over 60% of our operating expenses. We participate in the overall Barth Syndrome Foundation grant program which is administered by Matt Toth, Scientific Director. Once we have heard reviews of all the grant applications, the Canadian Board of Directors votes on which of the eligible grants, if any, we will participate in funding. In addition to the scientific criteria, there is a specific list of agencies that Canadian charities are eligible to fund, and fortunately many of the Barth syndrome related grant requests that are recommended by our SMAB come from eligible agencies.

(Cont'd on page 25)



(Cont'd from page 24)

In the 2008 grant cycle, we are involved in funding the following grant:

***“The role of tafazzin in mitochondrial protein import – Implications for Barth syndrome”***

**Miriam L. Greenberg, PhD, Wayne State University**

\*Funding provided by Barth Syndrome Foundation and Barth Syndrome Foundation of Canada

During the 2007 grant cycle, we were involved in funding the following grants:

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

**Richard Eband, PhD, McMaster University**

\*Funding provided by Barth Syndrome Foundation of Canada

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

**Christopher McMaster, PhD, Dalhousie University**

\*Funding provided by Barth Syndrome Foundation and Barth Syndrome Foundation of Canada

Other key areas of focus in this program in 2008 included sponsoring two Canadian medical participants to attend the International Conference and sponsoring the poster session at the Conference.



*(Clockwise): Robert, Adam, and Jared at the Roaring 20's social event at our 2008 International Conference.*

*(Photo courtesy of BSF ~ 2008)*

## Living with Barth Syndrome

*By Robert Hope, Canada*

I was asked to write an article on what it is like for an affected individual to live with Barth syndrome. This disorder affects everyone differently at various stages of their life. In order to get a cross section of outlooks and attitudes I asked some of my closest friends that I met through the BSF organization. Barth syndrome is something that we live with everyday, and asking us to describe what it is like to live with it is like asking a person what it is like to write with their right hand. We deal and face it in our own way.

Some of the responses I actually received are as follows:

**“Having Barth means that I have to be aware of what my limits are and not over exert myself while working. Yet I do not let it control my life. I control it.” ~ 22 year old Barth Individual**

**“Living with Barth Syndrome has given me an opportunity to share my unique experience with others, including those studying to be doctors.” ~ 20 year old Barth Individual**

**“Well in my opinion Barth syndrome is a nasty piece of work. It makes me really, really tired and also really hungry all the time.” ~ 10 year old Barth Individual**

Hopefully these statements will provide some insight into the lives of those boys and men that live with this disorder and its challenges everyday, and yet face those challenges with all of their courage.



# Canadian Volunteers Tackle 2009

By Lois Galbraith, Barth Syndrome Foundation of Canada

On January 24, 2009 our fabulous volunteers gathered at the home of Audrey Hintze to hear about the Barth Syndrome Foundation of Canada's (BSFCa) program plans for 2009 and to roll up their sleeves and begin planning of their own. The room was alive with new ideas, opinions, great questions, many serious suggestions and the usual high level of enthusiasm.



*(L-R): New volunteers Paula and Lindsay join Audrey and Carol as new ideas are discussed at the volunteer meeting. (January 2009)*

In attendance were Carol Wilks, Jan Humphries, Audrey Hintze, Paula Sisson, Maureen Pitkethly, Lynn Elwood, Robert Hope, Celia McGuinness, Chris Hope and Lois Galbraith.

The business, fundraising and activities of the BSFCa are all volunteer driven and we are very fortunate to have active and enthusiastic folks with us.

Our volunteers at the meeting that Saturday helped us to formulate plans in most of our programs. They agreed to perform web searches for our charity support and awareness areas. They listened intently and were able to find ways of getting the word out to researchers. In a discussion of our newsletter, they suggested that we include our accomplishments along with a "wish list," and they expressed their opinions about the types of articles they would like to see included. Volunteers Wayne and Dianne Bridger wrote an article for the March 2009 issue. Individual fundraising ideas were also discussed.

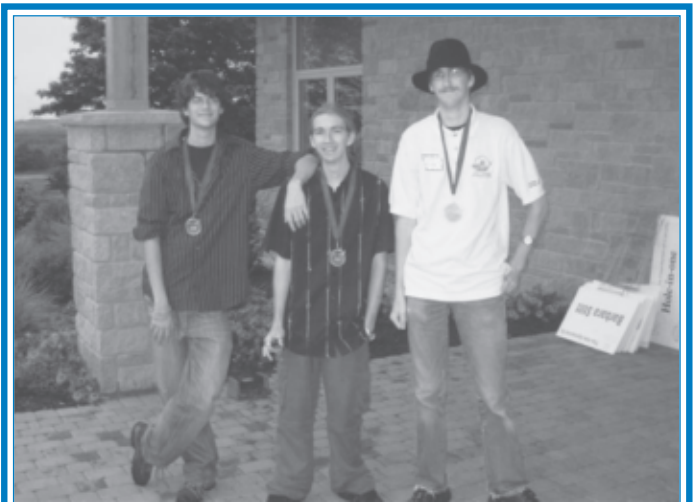
Lindsay updated the group on her awareness efforts for the BSFCa. She and two friends from school entered a Youth and Philanthropy Initiative (YPI) competition. They chose the BSFCa as their grass roots, non-profit organization in the community. Lindsay explained how they researched Barth syndrome. They eventually produced a power point presentation and an oral dissertation. She provided us with a copy of their informative and professional brochure on the BSFCa.

Our volunteers continue to surprise and delight us with their love, caring support and their ever-fresh ideas.

We came away enthused and buoyed by the spirit of this group and ready to tackle 2009 together.



*(L-R): Maureen, Lynn and Robert listen and learn from the fresh ideas the volunteers bring to the meeting. (January 2009)*

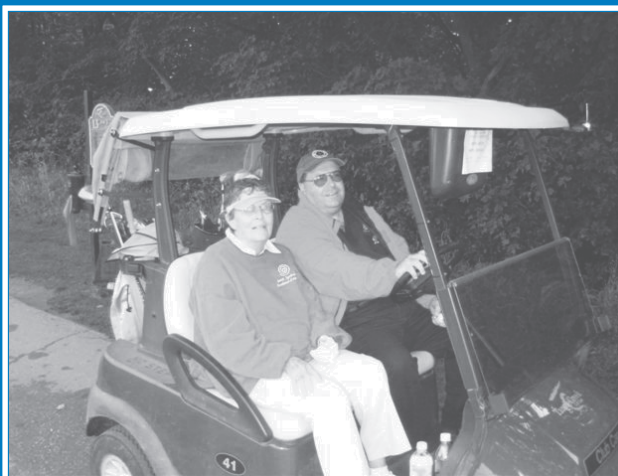


*(L-R): Our Barth heroes, Ryan, Adam and Robert as they helped out at the 4th Annual BSFCa golf tournament. (September 2008)*

# Celebrating its Fifth Year!

## *BSFCa September Golf Classic*

Monday September 14, 2009  
Tangle Creek Golf Club



*Mother and Son Golfers/Supporters: Helen and Michael Hope.*

*(September 2008)*

Monday September 14, 2009 will mark our fifth annual golf tournament at award-winning Tangle Creek Golf Club in Barrie, Ontario, Canada. These golf days have been very exciting and filled with fun, camaraderie and great golf!

When we began planning the first tournament we were filled with more questions than answers but also with great enthusiasm and fantastic support and encouragement from many people. We raised \$13,000 that first year and we learned many lessons.

We continued to be excited by the support, encouragement and ideas from friends, families and golfers when we embarked on our second, third and fourth tournaments.

We have relied on resourceful people for time and advice. We have drawn upon family, friends and colleagues for prizes and sponsorships. We have had a core of corporate sponsors who have believed in our cause and have been there with us! Our total funds raised by 2008 were \$70,000.

To succeed it takes drive, determination, organization, fundraising and a strong desire to beat this disorder. We have all of these abilities and the many volunteers that are needed as we head into our 5<sup>th</sup> golf tournament.

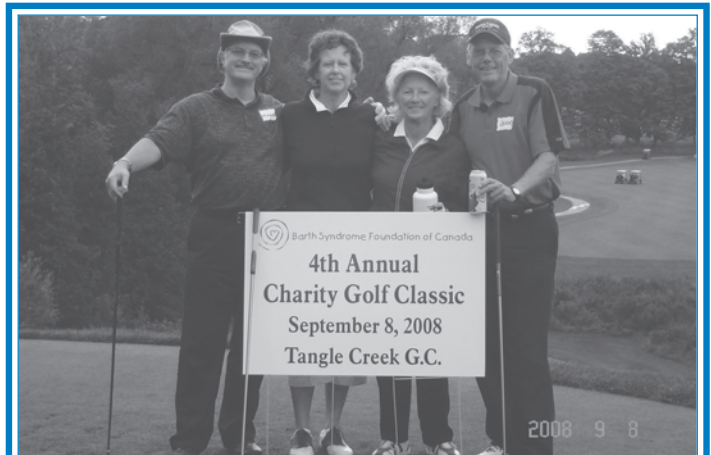
We owe much of our success to many people who have believed in the BSFCa and in our desire to press forward for this cause.

We ask you to set aside Monday September 14, 2009 and join us at Tangle Creek Golf Club. We have had annual golfers and folks from Nebraska (Mike Wilkins) and Merritt Island, Florida (Jan Kugelmann, Sharon Olsen, Joanie Weaver). We have also had hole sponsorships from the United States (Wilkins family) and as far away as Scotland (Anderson family).

We welcome all golfers and sponsors. If you would like more information about our fifth annual golf tournament please email [lois.galbraith@sympatico.ca](mailto:lois.galbraith@sympatico.ca).



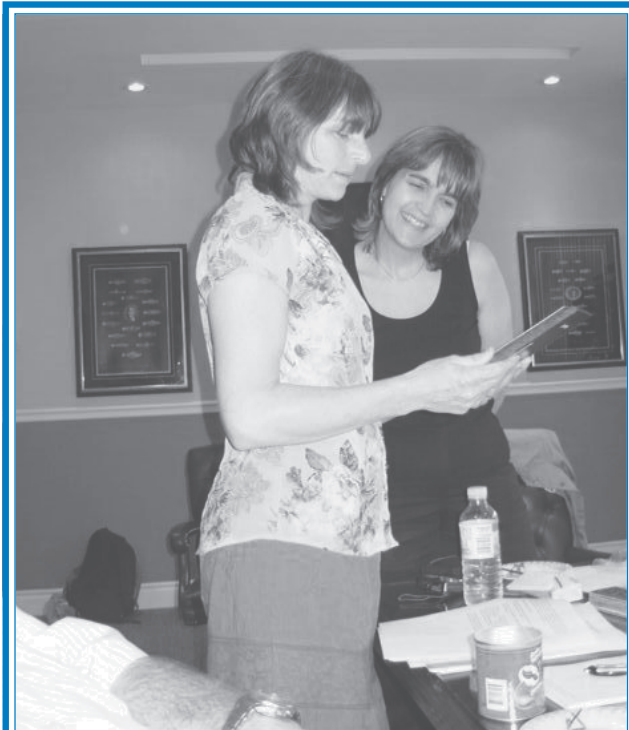
*A Family Affair (L-R): Wilmer Deforest, Kevin Dupont, Lorraine Deforest, and Warren Deforest. (September 2008)*



*Faithful supporters (L-R): Stuart and Jody Burns with Janet and Jerry Warren. (September 2008)*

# An Exciting Event for Canadian Stakeholders

By Les Morris, Barth Syndrome Foundation of Canada



*Chris Hope, Board Member, receives an award for outstanding service from the President.*

*(April 2009)*

How do you make an annual general meeting be interesting and provocative?

It all started when one of our Board Advisors, Ian Morris, allowed us to use his office facilities which were not only spacious and comfortable but also came free of charge.

We coupled the AGM with an outreach program which allowed members and families to enjoy more social interaction before, during and after the business meeting.

Our President, Lynn Elwood, began the proceedings with the tragic story of the loss of Michael Telles, a young Barth boy from Texas. His photo was distributed and followed by a moment of silence. Although this announcement was extremely emotional and brought tears, it also served to strengthen our resolve to become even stronger as an organization.

The meeting continued with reports from program leads outlining our many successes in the past year and our plans for the future. The details and complexities of these reports made everyone aware of the significant amount of progress made and the plans established. We were reminded of the BSFCa planning weekend that took place and of the significant contributions of each and all of our volunteers. Financial reports were received and approved. The interests and questions that were entertained during both the formal and informal times brought forth many new ideas.

Special mention was made of the outstanding efforts of our Board members, Lynn Elwood, Chris Hope, Cathy Ritter, Susan Hone and Karen Gordon who have spent a decade founding the Canadian organization and leading it to its present level while working at their professions and supporting their families.

The atmosphere of this AGM/Outreach was enhanced by refreshments provided by volunteers. Following the business meeting we all adjourned to a nearby restaurant where, thanks to an arrangement from another volunteer, hors d'oeuvres were served free of charge and a wonderful time of mixing, mingling and merriment was enjoyed by all.



*Executive members and volunteers hard at work at our AGM.*

*(April 2009)*



*President Lynn with our Barth men Robert and Ryan.*

*(April 2009)*



*Well earned relaxation following the AGM!*

*(April 2009)*

# Sibling Spotlight

## Featuring friends from around the globe

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



**Name:** Celine

**Age:** 8

**Where are you from?**

Victoria, Australia

**What are your hobbies?** Playing DS, computers, and playing with my cats.

**Affected siblings?** Robert (age 18+) and Jacob (deceased May 29, 2002)

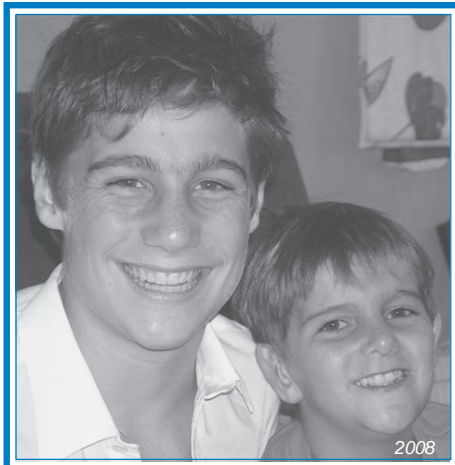
**What do you like doing with your brother?** Playing Nintendo Wii, loving, hugging and play fighting with him.

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

Be happy, hug and love each other more. I feel blessed to be given the strength to help other children as the heart represents love and compassion. This is what I learned from both my brothers Robert and Jacob, who I miss dearly.

**What does BSF mean to you?**

It helps affected children and is trying to find a cure for them.



**Name:** Tom

**Age:** 16

**Where are you from?** South Africa

**What are your hobbies?** Sports (mainly rugby and waterpolo), going to the beach, playing guitar, meeting new people, and going to new places.

**Affected sibling?** Ben (age 14+)

**What do you like doing with your brother?** Well, he can't do much physical activity but we pass a rugby or soccer ball around, swim, and watch T.V. Or we just relax and chat.

**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 just tell them that they shouldn't treat their brother any differently because of it. It is not something their brother would want them to do. They should just offer all the help and support they can and I'd say that they would probably have a better relationship with one another.

**What does BSF/BTrust S. Africa mean to you?**

It means a lot because it creates awareness for doctors and families who might come across Barth syndrome and would otherwise not know what it is. More research done by different doctors around the world can only help.



**Name:** Jessica

**Age:** 26

**Where are you from?**

Saskatchewan, Canada

**What are your hobbies?** Computer, video games, comic books, drawing, singing, karaoke, and reading.

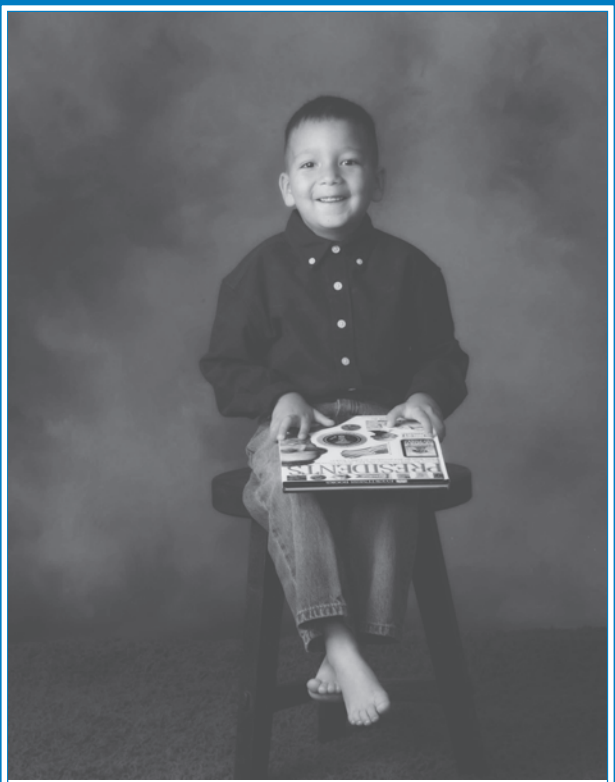
**Affected sibling?** Jared (age 15)

**What do you like doing with your brother?** I enjoy singing and dancing with him, yelling at game shows together, and running over Josh with Jared's wheelchair. Jared has taught me to have a greater understanding of people with disabilities. I love his laugh and the way he laughs at all the wrong jokes. He is good natured despite all the obstacles in his life.

**If you met someone who had just found out that their brother had Barth syndrome, what would you say to make them feel better?** They are not alone, there is a great support network out there. Help to get them in contact with others, provide information, and direct them to the website. I would share my personal experience of having brothers with Barth syndrome and being a carrier of the gene.

**What does BSF/BSFCa mean to you?** It brings people together, gives families a support system, information at your fingertips.

# In Memory of Michael Anthony Telles Jr.



*Michael Anthony Telles Jr.  
Texas, USA  
11/25/2001 ~ 04/20/2009*

Michael Anthony Telles Jr., 7, our most precious and beautiful boy, left this world and made his way home to Heaven, Monday, April 20, 2009, surrounded by his family and held by his mommy and daddy. The Mass of the Resurrection was held on Friday, April 24, at St. Anthony Marie de Claret Catholic Church in Kyle, Texas. Interment followed at Memory Lawn Cemetery in Martindale, Texas.

Michael Anthony Telles Jr. was born Nov. 25, 2001, to Michael Anthony and Linda Michelle Telles in Austin. From the moment he entered this world, he began touching every person that ever saw or met him. He had a smile that would make you melt and a strength that was boundless. He loved to hug his mom and dad every chance he got and he always let them know how much he loved them. He loved to read as many books as he could and then tell everyone around him what he just learned. He spent his time playing with his little brother, Matthew Alexander Telles, whom he loved with all his heart. He tried to teach him all that he knew and watch over him when they were together. Michael's favorite book was a book on the U.S. presidents, and he loved to play his guitar, eat queso and his daddy's pico, and reenact quotes from his favorite movies and shows. He loved all his teachers and friends at Fuentes Elementary, where he was in the first grade. His biggest source of pride was coming home with a purple sticker to show his mommy and daddy. He talked nonstop about how much fun he had every day at school.

The family wants everyone to know Michael's heart was so full of love that if you loved him, he loved you back ten times more. He knew and remembered each and every one of you, and you became a part of his heart and memories. Michael's impact on our lives can never be written or expressed since all that he taught us is immeasurable. He filled the life of his family and friends with so many wonderful memories and

moments that are priceless. Each and every moment we were with Michael was truly a gift from God. We are so lucky that God chose us to have the gift of Michael for these past seven and one-half years. We know he probably sang one of his newest favorite songs, "Yes Lord" on the way to heaven, where he is surrounded by all the angels and saints. Michael is now receiving his reward in heaven and will forever be looking down upon us. In heaven, Michael has his great-grandpa Garcia; great grandma and great-grandpa Martinez; uncle, John Paul Garcia; cousin, Mike Torres; neighbor, Tom Elliott; many cousins; and his Barth brothers who surround him. Michael leaves behind his most loving and devoted parents, Michael and Michelle Telles; loving little brother, Matthew Alexander Telles; grandparents, Elisa Flores and Rudy and Lin Garcia; aunts, Lisa Ramirez, Christine Martinez and Lisa Duran; uncles, Stephen LaFuente, Johnny Ramirez, Rudy Garcia, and Henry Duran; cousins, Arlene Castillon, Robert Mendoza Jr., Joseph Salgado, Roy Norgan V, Israel Gomez, Stephanie Ybarra, Freddy Ybarra Jr., Amor Ramirez, Esai Ramirez, Juan Ramirez, Rudy Garcia Jr., Elena Garcia, Gabriel Duran, Jason, Sabrina, Isaiah and Leiyah; his other amazing aunts, uncles, and cousins; his Barth brothers; and the countless friends he made during his life.

The family would like to thank all the amazing doctors and nurses that helped Michael during his lifetime, especially Dr. Mouser and Dr. Shapiro; and those that took care of him in Dallas. Each doctor did all they could to help Michael while he was here with us. In lieu of flowers, the family has asked that donations be made to the Barth Syndrome Foundation.

On behalf of BSF, we would like to express our gratitude to the Telles Family for requesting donations be made to BSF in lieu of flowers. Donations continue to be received by loving family members and friends in memory of Michael Anthony Telles Jr.

# In Memory of John C. Grzesiak, Father of a Barth Son



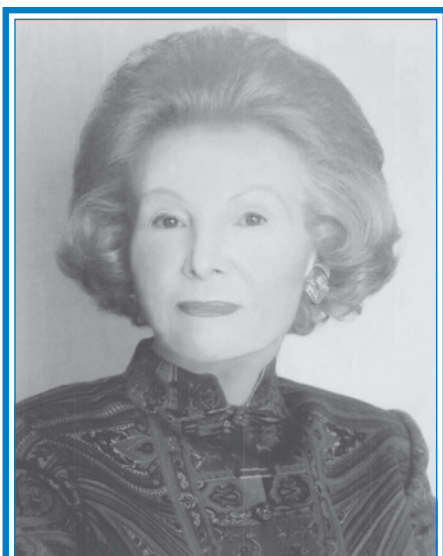
*John Grzesiak and his son at BSF's 2008 Conference. (Photo courtesy of Amanda Clark)*

GRZESIAK, JOHN C., 34, of Johnston, Rhode Island, died Sunday May 3, 2009 at home surrounded by his family. He was the beloved husband of Lisa J. (Generali) Grzesiak.

John was born in Calumet City, Ill., a son of Richard, Sr. and Eileen (Stephens) Grzesiak of Johnston. John was a Field Service Representative for Cox Communications for five years before retiring due to illness and an avid bass fisherman.

John leaves his wife and twin sons Matthew C. and Tyler J. Grzesiak. He is also survived by his sister Debra A. Conley and her husband Patrick of Bristol; his brother Richard A. Grzesiak, Jr. of Johnston. He was the brother-in-law of William and Michael Generali; uncle of Annie, Brendan and Christina Conley, Kristopher, Anthony and Damion Generali.

# In Memory of Mrs. Leonore Annenberg, Loyal Donor



*Mrs. Leonore Annenberg  
02/20/1918 ~ 03/12/2009*

One of our greatest and most loyal supporters, Mrs. Leonore Annenberg, passed away on March 12, 2009 in Rancho Mirage, California. Her family's spokesperson said that she died of natural causes and that her family was by her side. Mrs. Annenberg was 91 years old. She is survived by a sister, two daughters, one step daughter, seven grandchildren and eight great-grandchildren.

For those of you who may not know, Mrs. Annenberg was one of our first and most important supporters, providing a grant to the Barth Syndrome Foundation in our very first year in support of research into Barth syndrome. She had faith in our determination and ability to make a real difference in our children's lives at a time when we were unknown and untested. I believe that it is fair to say that Mrs. Annenberg's initial donation gave us the confidence to build our Scientific and Medical Advisory Committee and invest in the research that may someday cure our children. She soon followed that initial donation with others, helping to sustain our investment in science and research over the last nine years.

For many years, Mrs. Annenberg asked that her donations be kept anonymous and many close readers of our Newsletter knew that BSF had a special "Angel" who provided some of the wind beneath our wings. She held us to high standards, requesting regular reports on our progress and expecting that we would run BSF with the same care and professionalism with which she ran the Annenberg Foundation. Like a loving parent, Mrs. Annenberg set the bar high and then helped us to rise above it.

Only recently did she allow us to let you know who our anonymous donor really was. Mrs. Annenberg's last gift to BSF was announced during the Conference last year in Florida—again, a donation in support of our scientific programs, but with the flexibility to use as we saw best. To the end, she communicated a confidence and faith in our efforts that will sustain us for many years to come. The Barth Syndrome Foundation, and our global Barth community was only one small group that benefited from her quiet support and guidance...many large and worthy causes also benefited from her generosity. But none can claim a deeper nor more personal sense of loss at her passing than we. She left our little portion of the world a far better place than she found it—and she did so with no wish for thanks or acknowledgement. We could ask for no better friend. Our prayers and condolences go to the Annenberg Family, and to her friend, Mary Baffa.



### PAULA & WOODY VARNER FUND

#### Stars (\$5,000+)

Dillon Foundation  
Wilkins, Dr. Mike & Sue  
Yanney, Michael & Dr. Gail

#### Angels (\$1,000 - \$4,999)

Cheatham, Dr. John & Linda  
The New York Community Trust  
Voell, Richard

#### General Contributions (\$50 - \$999)

Acklie Charitable Foundation  
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Allman, Tom  
Basler, Dr. Rod  
Beynon, Dave & Liz  
Bingham, Dr. Dave & Kathy  
Brehm, Russell & Louise  
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Burmeister, Charles & Marita  
Burmeister, Jon & Jackie  
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Campbell, Candace & Robert  
Deeter, Doug & Leslie  
Desmond, Sally  
Dittman, Alice  
Farrar, Doug & Shawn  
Firestone, Dave & Jane  
Gelber, Dr. Ben & Elaine  
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Hedgecock, Norm & Debbie  
Henricks, Dr. Bruce & Peggy  
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Keating, Barbara & Con  
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Kiechel, Dr. Fred & Vivian  
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Lincoln Community Foundation  
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Steely, Robyn  
Stohs, Dr. Gene & Kristen  
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The Kubly Family Foundation  
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Wilkins, E. Joanne  
Wilkins, Marilyn  
Wilson, Dr. Chuck & Linda  
Wilson, Katherine

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#### Stars (\$5,000+)

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Barad, Seth & Amy  
Cusack, Tom & Carrie  
McCurdy, Steve & Kate  
McKown, Christopher & Abby  
Neff, George & Elizabeth  
Sernel, Marc & Tracy  
The Annenberg Foundation

#### Angels (\$1,000 - \$4,999)

Bealight Foundation  
Davis, Martha  
Kelly, Al & Peggy  
Kirkland & Ellis Foundation

#### General Contributions (\$50 - \$999)

Bill and Melinda Gates Foundation  
Harrigan, Lori  
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Telles, Michael & Michelle

### GENERAL FUND

#### Stars (\$5,000+)

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American Express Employee Giving  
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Blumenthal, Richard & Cynthia  
CB Richard Ellis  
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Lummis, William & Dossy  
Lummis, Marilyn  
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Malkin, Scott & Laura  
McCurdy, Steve & Kate  
Russell, Dr. Paul & Allene  
The Frill Foundation

#### Angels (\$1,000 - \$4,999)

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Matelich, Susan & George  
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Schwab Charitable Fund  
Schwartz, Mark & Marie  
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The New York Community Trust  
Chang, Kim (TKNY Group, Inc.)

Tortimaki Foundation  
Vaisman, Beth & Natan  
Winston, Laura

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Abbonizio, Leita  
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Acklie Charitable Foundation  
Adlam, Dr. James & Patricia  
Akin, Martha  
Alcabes, Elisa  
Alise, Sr., John  
Allen, Dr. Answorth  
America's Charities  
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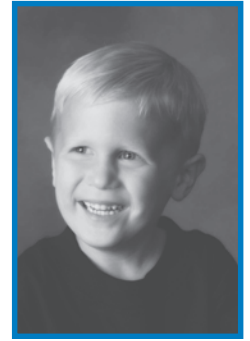
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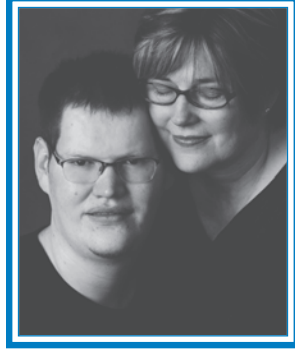
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Mendes, Lynsi  
Merrill, Debra  
MGM Insurance Agency Ltd.  
Millar, Margaret  
Millar, Ronald  
Miller, Pickard Law  
Milne, Peter

Moffat, Heather  
Molinaro, Elvi  
Morris, Cherniak  
Morris, Dianna  
Morris, Elsie  
Morris, Ian  
Morris, Les  
Morris, Pam  
Mullen, Lea  
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  
Patrick, Barbara  
Pearce, Bev  
Pearce, William  
Performance in Motion  
Perkins, Phyllis  
Piasecki, Jon  
Pick, Brian  
Pike, Pam  
Pitkethly, Maureen  
Poitras, Mike  
Poitras, Sandi  
Poole, Bob (Aerostructural Inc.)  
Post, Michael  
Power, Carolyn  
Prodan, Magda  
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  
Rodgers, Jim  
Ross, Barbara  
Roy, Larry  
Royal & Sun Alliance,  
Rush, Aaron  
Rutenberg, Karen  
Sandelovich, Joyce  
Sandelovich, Robert  
Sawh, Harold  
Sawh, Ruby  
Schuller, Dennis (Aviall Canada Ltd.)  
Scothorn, Pam  
Scott, Bob (MxAerospace Services  
Inc.)  
Scott, Jeffrey  
Sedefian, Lynda  
Segal, Joseph  
Selkirk, Kim  
Sharpe, Wade  
Shaw, Blaine (Mississauga Classic  
Car Club)  
Sheppard, Jamie  
Sisson, Lindsay  
Sisson, Paula  
Skopit, Barry  
Slepkov, Martin  
Sluzar, Daniel  
Sluzar, Mark  
Smith, Glenn  
Smith, Ted  
Smolak, Roman  
Smolic, Alex  
Smolic, Joe  
Snowden, Mary  
Souter, Caroline  
Stabb, Susan  
Stevens, Mike  
Stitt, Barabara  
Stoll, Brian  
Storey, Andrew  
Storey, Dick  
Storey, Janis

Street Classics Cruise  
Stundis, Linda  
Sturupp, Penny  
T.D. Bank,  
Taylor, Dean  
Taylor, Susan  
Thomas, Brian  
Thorpe, Jeanette  
Timpleck, Barry  
Tjart, Gwen  
Tjart, Richard  
Tomlinson, Annette  
Tomlinson, Brian  
Tomlinson, Danny  
Tomlinson, Shannon  
Torrence, Erin  
Toth, Matt  
Trillium Gift of Life Network  
Trim, Norma  
Trim, William  
Trueman, Carole  
Tsilikas, Alana (Kelsey's 7066)  
Turner, Dave  
Turner, Ron  
Tweed, Scott  
Vandemeer, Carl  
Vanderwater, Barbara  
Vella, Betty  
Vilneff, Bill  
Vilneff, Rita  
Vine, Edward  
Vine, Rosa  
Wallace, Gary  
Waller, Cliff  
Warner, Tramp  
Warren, Janet  
Warren, Jerry  
Weaver, Joanie  
Webb, Lindsay (Lindsay Webb  
Financial Inc.)  
Weeks, Ken  
Wegman, Gelja  
Wegman, Rick  
Welch, Dave  
Weller, Sharon  
White, Leone  
Whitmore, Connie  
Wild, John A.  
Wilkins, Mike  
Wilkins, Sue  
Wilks, Bruce  
Wilks, Carol  
Wilks, David  
Wilks, Dennis  
Wilks, Helen  
Wilks, Maddy  
Williams, Matha  
Wilson, Ron  
Wiwcharyk, Lubow  
Wong, Belle  
Woodcock, Roy  
Woodcock, Sharon  
Wuthrich, Grace  
Xerox Canada,  
Young, Dorothy  
Young, Lenore  
Young, Ron  
Zilcor, 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 on the natural history, biochemical basis, and treatment of Barth syndrome anywhere in the world.

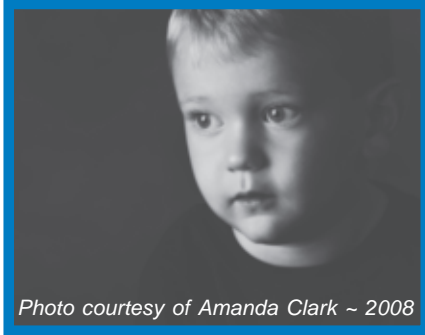


Photo courtesy of Amanda Clark ~ 2008

## 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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Barth Syndrome Foundation, Inc.  
[mtoth@barthsyndrome.org](mailto:mtoth@barthsyndrome.org)

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



Barth Syndrome  
Foundation

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