Barth Syndrome Foundation
www.barthsyndrome.org

Barth Syndrome Journal

Volume 10, Issue 1 Spring 2010

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

10th Anniversary

Inside this Issue

BSF is a proud member of the National Health Council

A Decade of Growth and Accomplishment

By Stephen McCurdy, Chairman; Shelley Bowen, President, Barth Syndrome Foundation

In 1998, Shelley Bowen, Anna Dunn and Sue Wilkins found each other on the Internet as they searched for others with children like their own… children with Barth syndrome. Aided by Dr. Richard Kelley at the Kennedy Krieger Institute at Johns Hopkins and supported financially by Sue's Mother, Paula Varner, these three Moms gathered together 27 Barth families from four continents, along with 5 scientists and 16 doctors from around the world for the first international Barth syndrome gathering in Baltimore, MD on June 16–17, 2000. Most of the families who were there had never met another person with Barth syndrome, let alone an entire roomful!

It may be hard to imagine today as we share questions, support and experiences with families from around the world on a daily basis on our BSF Listserv, but there was a time when Barth families were alone, not knowing if there was another Barth child alive in the world. There was a time early on when only very persistent doctors would recognize and research the various symptoms of the disorder and find one of the first few papers published on the condition before the mid 1990's—the first being by Dr. Peter Barth from Amsterdam in 1983—and reach a diagnosis of the disorder later dubbed "Barth syndrome."

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Seven Grants Awarded for BSF's 2009 Research Grant Program

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

The 2009 BSF Research Grant Program fielded the largest numbers of applications in this its eighth year. The quality and geographic diversity of the applicants for the 2009 cycle was impressive which made decisions about funding the most difficult it has ever been. This difficulty demonstrates that the reach of the BSF through its Research Grant Program is truly global and is increasing in quality. Please see page 12 for a summary of the main focus for each of the seven grants awarded, with some thoughts about the value each will bring towards achieving our ultimate goal.

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A Decade of Growth and Accomplishment

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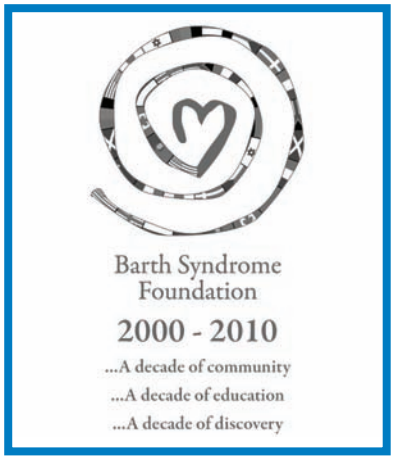

That meeting in Baltimore was a transformative experience for everyone present because, for the first time, there was hope. There was hope in the smiles and shared experience of other families—others who quite simply "got it"; hope in the wisdom and gentle intelligence of doctors and scientists like Dr. Barth, Dr. Kelley, Dr. Gerry Cox from Boston Children's, and Dr. Iris Gonzalez from duPont Children's Hospital, all of whom have served on BSF's Science and Medical Advisory Board from the beginning; and hope in the formation of the Barth Syndrome Foundation, a step forward from the informal Barth Syndrome Family Network which preceded it.

BSF was officially incorporated on September 9, 2000 and received IRS provisional recognition as a charity on January 9, 2001. Since then, this tiny band of determined families and their friends (old and new-found) have accomplished so much more than was even dreamed by those who sat on the floor of a barren, free meeting room in the Mount Vernon Hotel in Baltimore ten years ago. There are now over 125 families in our community and three additional International affiliates of BSF in the UK & Europe, Canada and South Africa. BSF's loyal and generous donors have contributed almost $6 million through 2009 and helped to fund four International Scientific, Medical and Family Conferences and $1.7 million in research grants of up to $40,000 each. Now 50 of the ever growing list of peer-reviewed scientific and medical articles about Barth syndrome acknowledge the direct support of a BSF or BSF affiliate research grant(s). There is now a Barth Syndrome Medical Database and Biorepository available to support clinical and scientific research, a key asset in assessing the viability of any proposed treatments. Our scientists have developed "Barth" yeast, zebrafish, fruit flies and now a mouse model, all of which are critical accomplishments in the drive toward a deeper understanding of Barth syndrome and, ultimately, a cure.

Once again, the Barth community will gather at our International Conference in late July in Orlando, Florida. Families who are known to each other only via the Internet and families who have been close friends for 10 years will greet each other with open arms. Some 50 children with Barth syndrome are expected to attend the clinics, enriching the Barth Medical Database and Biorepository and accelerating the learning of the scientists and clinicians in attendance, who would never have the chance to see so many children and young men with this rare disorder in one place otherwise. And the researchers and scientists will be engrossed in two solid days of presentations, discoveries, discourse and collaboration, all toward our common cause.

So many people will be present… and so many people will be missing. For Barth syndrome is still a deadly disorder which takes our children long before their time. And yet, also present will be the parents of several boys and young men whose memories will forever be fresh in our minds. Strong communities and families share their knowledge, their strength and their grief, always quietly present when needed and ready to be a protecting and loving home for their members. And in the end, this may be one of our most enduring accomplishments.

A Path To Our Future

By Stephen McCurdy, Chairman; Shelley Bowen, President, Barth Syndrome Foundation

One of the most important roles for the BSF Board is to chart the future path of our Foundation toward our vision. As is often said, "if you don't care about your destination, any path will get you there!" But in our case, we have always been clear about our destination—we need treatments and a cure for Barth syndrome for our boys and young men. The question for us is "what is the path that will get us there fastest and what will it take to get on it and stay on it?"

Nearly a decade ago, when we first translated our collective dreams into a strategic plan, the five parents sitting around Anna Dunn's kitchen table clearly understood two things: that Barth syndrome was a very rare and virtually unknown disorder which would make finding families, raising money and attracting the interest of researchers very difficult… and that none of us had had any meaningful experience creating foundations, raising money or doing medical research. Instead, we were blessed with the three most important elements of success for any entrepreneur: drive, determination and optimism! There is no greater motivation for a parent than saving the life of their child. And when faced with a challenge that would stop more experienced, knowledgeable people in their tracks, our motivation only served to feed our determination. Finally, and perhaps most important, we found ourselves surrounded by proactive and fundamentally optimistic people; people who, against all reasonable odds, believed that they could and should solve this problem themselves rather than wait for "somebody else" to do it. **These characteristics—motivation, persistence, a positive attitude—continue to form the core of the culture of our BSF community.**

We believe that we can only achieve our vision if we succeed in building a strong community with a single overriding goal and a culture of selfless dedication. From the beginning, we included in our plan all five of the **constituencies upon whose success our vision depends: families, physicians, researchers, contributors and volunteers/staff**. We have also found that every single group is dependent on the cooperation of the others and that **all must advance together or none will advance optimally**. Our strategy for the next decade will continue to reflect this understanding.

As was true from the very first meeting, **families form the core of our strategy.** Barth syndrome is a genetic disorder that directly affects (almost exclusively) males from birth. Because it is genetic, chronic, and can be fatal, Barth syndrome profoundly affects every member of an extended family including parents, grandparents, aunts and uncles and siblings. Its rarity has meant that there has been little that is known about the disorder and more importantly, how to treat it. Parents, usually mothers, have been forced to become the medical "experts," using their instincts and their experience to guide physicians in the treatment of their children. As a result, BSF has had to create opportunities for parents to share their experience and to benefit from the **"wisdom of the group."** Our **Internet Listservs, affiliate and regional outreach gatherings and biennial International Barth Syndrome Scientific, Medical and Family Conferences** all serve this purpose, as well as cementing the bonds of a growing community and insuring that parents who find BSF will never have to feel their way blindly through the darkness of loneliness and ignorance again. These programs will not only continue but will grow.

Rarity and lack of clinical exposure or documented history often leaves clinicians as much in the dark as parents when a child presents with life threatening symptoms "of unknown origin." In real life, "Dr. House" can rarely save the patient in a single hour-long episode, popular TV shows to the contrary! So having physicians and researchers document what is known and create **treatment guidelines** that will be broadly read and respected by the

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A Path To Our Future

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medical profession continues to be a major goal for BSF. Our **clinics**, which precede every International Barth Syndrome Conference and many regional outreach gatherings, are invaluable not only to the clinicians who attend but also to the clinicians who later read about discoveries that have been made on the basis of clinical data collected at these events. Where else can 50 boys and young men with a rare disorder be examined and interviewed in the space of two days? What better place to gather, organize and record the extensive medical data and obtain DNA, tissue and blood samples for the **Barth Syndrome Medical Database and Biorepository**—a resource which is critical to ongoing research and which will form the baseline for comparison for the effectiveness of any treatments that research will develop? These programs too, must continue and grow.

The single most challenging aspect of a rare disorder is always its rarity. And while BSF and our affiliates continue to find more families around the world, our numbers are still very small. Can there be any more important and central goal for BSF than finding ways to accelerate our search for new families? To date, we have relied on our **website**, our **attendance at medical and scientific meetings** and **public relations efforts** (BSF families have appeared in Reader's Digest, Parade Magazine and many local or regional newspaper stories; and on the Today Show on NBC, the Discovery Channel and numerous local TV stations) to help newly diagnosed families find their way to BSF. We must continue to seek opportunities to **raise awareness of Barth syndrome and build the credibility of BSF among the medical community and the general public**.

We have also been assisted by several medical testing labs who pass on information about BSF to doctors when a positive test for Barth syndrome helps a doctor reach a definitive diagnosis. Sometimes this information reaches the family, and sometimes it does not. Sometimes a family contacts us immediately… and sometimes they go to our web-site but never reach out to us. Some never contact us at all. Because no one else has the motivation to do so, BSF must work with members of the medical and scientific community to improve every stage in the process leading to a family receiving a confirmed diagnosis and contacting BSF: **educating physicians to recognize the clinical symptoms of Barth syndrome**; developing **quick, low cost definitive tests to confirm the diagnosis**; encouraging **qualified labs** around the world to make the tests available; even working with state and regional authorities to include Barth syndrome in **newborn screening**, which can take 10 years or more. It doesn't stop there! Today, there is no universal diagnostic code (International Classification of Diseases code—ICD) for Barth syndrome. Effectively, without an ICD code, Barth syndrome is not easily recognized by the medical community, insurance companies or public health officials. Without an ICD code, public health agencies and researchers have no way to track or gather information on Barth syndrome as an independent disorder. BSF is working to help **create an ICD code for Barth syndrome**, but we know that this process too can take over a decade. In the meantime, the only way information on Barth syndrome can be gathered to spur research and discovery is through BSF and our Medical Database and Biorepository. Not surprisingly, the larger the number of families known to BSF and our affiliates, over many years, the greater is the warehouse of data and samples available to researchers and the greater the chance that scientists will develop more effective treatments and a cure. **Accelerating the search for more affected families should be an increasingly important part of BSF's plan.**

Research must be another critically important element of BSF's long-range plan. To date, our research program has been very successful. Our objectives were to stimulate basic research and the number of researchers focusing on Barth syndrome, increase the number of peer-reviewed scientific articles in respected scientific publications and encourage larger, better-funded institutions such as the NIH and the American Heart Association to devote considerable sums of their money to Barth and Barth related research. We did so by creating a Scientific and Medical Advisory Board and staffed it with accomplished scientists who are well known and highly respected in their fields. We created a **research grant program** that awarded small ($40,000) grants to qualified scientists who were committed to publish their results and then to build on their work and to seek larger grants. And we funded the creation of important parts of the infrastructure needed to encourage further research such as **several animal models** (including a "Barth mouse" which proved a particularly difficult task), our **Barth Syndrome Medical Database and Biorepository**, a comprehensive and easily accessed **library of every paper published on or relevant to research on Barth syndrome**, and our **International Barth Syndrome Scientific, Medical and Family Conference** that is held every two years.

However, it is becoming apparent that we can no longer simply wait for qualified researchers to become aware of our research program and submit grants of interest to them. We must seek out "cutting edge" researchers in fields that will become important arenas for new work on Barth syndrome and convince them to join our already strong team. Serendipity is a key part of any research effort, but so is directed research. We have already directed work into the development of animal models and enzymes. We still have too little understanding of genetic modifers that might cause the many clinical

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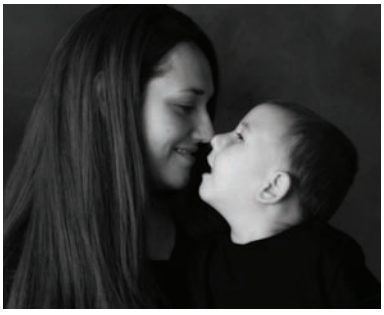
variants of Barth syndrome, and this is clearly an area for further investigation. But we also need to **expand our efforts beyond basic research into more clinical areas that can lead to drug discovery**. The specific direction of this research still must be determined, and we will count on our SMAB and research partners to help lead the way.

A simple review of the literature on drug discovery makes clear that this is a time and resource intensive process. The cover article in the May 24 and 31, 2010 double issue of Newsweek magazine entitled "Desperately Seeking Cures" lays out in clear picture and prose the complex and usually labyrinthine pathway from genetic cause to clinical cure for any disease, but particularly for a rare disorder like Barth syndrome. In order to navigate this course, BSF will need **ever greater infusions of funding and expertise**. And while we have been more successful to date than all but a handful of similar rare disorder organizations, BSF will have to step up our "game" to levels not previously envisioned. We will clearly have to **grow our cadre of incredibly devoted donors** who have funded our success to date, and we will need to grow and fund our team of researchers to push further into the current unknown—but knowable—areas of science. But it also seems clear that we will need to **find new, better funded partners** who can assist help us achieve our vision. We have the motivation, persistence and positive attitude, but we will need even greater amounts of time and treasure—volunteers and donors—if we are to reach our goal.

So after ten years, where are we? Clearly, we are much farther along toward our vision then we were when we sat on a floor in a meeting room at our first gathering at the Mount Vernon Hotel in Baltimore and decided to create BSF. Today, we have abolished the isolation and despair that characterized the lives of Barth families before 2000. We have grown and nurtured the Barth community to include families, donors, supporters, volunteers, staff members, dedicated researchers and caring clinicians into a devoted family with a common vision that did not exist in 2000. We know so much more and our children are living longer than they were ever expected to. But it is also clear that we have so much farther to go. Families are still losing their beloved children, and the community grieves together. We have so much more that we need to understand. Science offers the potential for a long-term solution, but only to those with the devotion, persistence and optimism to stay the course and the creativity and willingness to explore and adopt new approaches and new and better solutions. The good news is that those are the same characteristics upon which we founded BSF a decade ago. And today, we have all of you to help us along the way.

When faced with the daunting scientific and medical challenges of treating and curing Barth syndrome, the leaders of BSF have thought a lot about how we (who are almost all NOT scientists or doctors) can possibly make a real difference. After all, we cannot ourselves conduct the research nor write the prescriptions. But what we can do is to **facilitate** the work of those who can do those things and more. We can raise money to fund their important work. We can convene meetings at which they are all brought together to hear the latest science and offer them opportunities to brainstorm about the implications for Barth syndrome. We can identify and encourage specific scientists and physicians to get involved. We can contribute medical records to our Barth syndrome registry and donate blood and tissue samples to make it as easy as possible for scientists to do their work. And we can facilitate and support new exciting collaborations that expand current horizons and stimulate innovative thinking. All of these things greatly increase the chances that real progress will be made, and there is no one more interested in doing so than all of us. Malcolm Gladwell's most recent book Outliers: The Story of Success states that "success arises out of the steady accumulation of advantages"; our goal at BSF is to accumulate as many advantages as we possibly can… and we need the continued help of everyone reading this (and anyone else you know who could help) to do so.

The future is both unknown and frightening. But we have confidence in our direction and even greater confidence in the strength and dedication of our growing community to find a way. With clear eyes on the prize, devotion to and appreciation for each other and a willingness to continue to work together selflessly to reach our goal, we will find a way. Thank you all for being such a critical part of our team!



Barth Syndrome Scientific & Medical Conference

The passion to drive towards a cure

By Ashim Malhotra, PhD, Senior Fellow, Departments of Surgery and Cell Biology, New York University School of Medicine, New York, New York

I was introduced to Barth syndrome in June of 2006, when I started working as a post-doctoral fellow in the laboratory of Dr. Michael Schlame in the Department of Anesthesiology at the New York University School of Medicine. Academically, this post-doctoral training was a direct continuation of my graduate work during my PhD where I studied the biochemistry of a mitochondrial enzyme called Glycerophosphate acyltransferase, which is involved in the first step for the synthesis of phosphatidic acid. By the end of my doctoral career, I was trained in Biochemistry and Molecular Biology but had not worked in a field that was directly patient related.

Barth syndrome research was fascinating and tough! At the time of my joining, Drs. Schlame and Ren had just finished characterizing the first live animal model for the disease—the fruit fly model and published their findings in PNAS. My initial assigned project was to look at the three dimensional spatial orientation of mitochondria in live muscle tissue from fruit flies carrying tafazzin mutations to investigate whether tafazzin affected mitochondrial dynamics. This initial project was unsuccessful in my hands and caused a considerable degree of consternation. I moved on to more biochemical projects and began in earnest to look at this challenging disease, with limited availability of disease models.

Academic pressure and peer pressure to out-perform the next man is a strong and common motivating denominator to most. But it was taking its toll on my work. My first unexpected break came with an invitation to attend my first Barth Syndrome Conference in 2008. I feel that attending this meeting was crucial to whatever level of success I've had in Dr. Schlame's laboratory. It was here that I met and interacted with a lot of senior level scientists in a very intense, though genial atmosphere. Where other scientific meetings tend to engender a more competitive scenario, I could really feel the passion for a drive towards a comprehension of the basic biology of Barth syndrome among the scientists attending this meeting. The underlying focus was always the hunt for a better molecular understanding and progress towards a cure. I also benefitted from interacting with the families. Meeting wonderful young children affected by the disease and listening to young boys talking about their experiences really brought home to me the emotional and human aspects that most scientists tend to relegate somewhat to the back of their minds. I returned from this meeting a changed man and was incredibly proud when the following year I was awarded a grant by the Barth Syndrome Foundation to investigate the role of cardiolipin in the assembly of mitochondrial protein supercomplexes, a work that though essentially biochemical in nature, aids our understanding of the role of cardiolipin in mitochondria and thus brings us a step closer to understanding diseases arising out of cardiolipin deficiencies, such as Barth syndrome.

Attending the Barth Syndrome Conference and meeting children afflicted with this terrible disease was definitely an eye opener and a tremendous positive stimulator towards working harder at looking at the disease. I am indebted to the Barth Syndrome Foundation and all the members and scientists who have aided me through the years and made my research experience not only academically satisfying, but also a richer, deeper and more meaningful life experience.

"It was at BSF's 2008 Conference that I met and interacted with a lot of senior level scientists in a very intense, though genial atmosphere.

Where other scientific meetings tend to engender a more competitive scenario, I could really feel the passion for a drive towards a comprehension of the basic biology of Barth syndrome among the scientists attending this meeting.

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Ashim Malhotra, PhD

Barth Syndrome Family Conference

Building Momentum to Continue Fighting Towards our Goal

By Julie Floyd, Conference Committee, Barth Syndrome Foundation

JUST SAY YES! The Barth Syndrome 2010 International Scientific, Medical and Family Conference is fast approaching and **WE WANT YOU**! Words cannot really describe all the emotions one feels leading up to, during, and after this life changing time with family, friends that might as well be family, doctors, scientists, researchers, and clinicians from around the world. This Conference is an even more special occasion than usual because we will be celebrating 10 years of this wonderful organization. I am incredibly thankful that since my son's diagnosis in 2006, the Floyd family has been able to attend both conferences in 2006 and 2008, and we are ready to go for 2010! Our wonderful neighbors and church friends were so gracious to even fund our trip in 2006.

Here are my top 10 reasons to attend the 2010 Barth Syndrome International Conference:

1. The knowledge I gain about Barth syndrome (BTHS) from every single person in attendance.
2. Watching my affected son as he learns more about Barth syndrome and forges life-long friendships with other boys who have BTHS.
3. Watching my non-affected son and daughter as they identify with siblings of boys with BTHS.
4. Knowing that since I will be so close to Shamu at SeaWorld, I can't possibly look that bad this year in my swimsuit.
5. The Friday night Social. By the way, cameras are not allowed as far as I am concerned this year.
6. A wonderful vacation for my family that we otherwise would not spend the time or the money on.
7. Knowing that through our Clinic days, new treatments and protocols will come for our sons.
8. The most beautiful portraits that you will ever have of your family by the wonderful Amanda Clark and her staff.
9. The fun, music and entertainment provided by Kendall Lucas, and his hard work to record our sessions for those who cannot be present.
10. Okay, so I was only able to think of 9, but I got really close.

Now, how can you resist? If you have not already, please log on to BSF's website (www.barthsyndrome.org), register for the Conference, make your hotel reservations, and pack your bags (okay, maybe you can wait a little bit on the bag packing, but I am such a planner). This time together truly is the most special and memorable you will ever have. We continue as a group to move forward towards a cure for this horrible disease. Being present and involved at the Barth Syndrome International Conference helps us build the momentum to continue fighting towards our goal.

As my son has said before, "Mommy, I really don't like Barth syndrome. But mommy if I did not have Barth syndrome, I would not know 'big Ben'." My son met Ben at BSF's 2006 conference and a friendship began from there. I feel just as my son does! While I would not have chosen Barth syndrome for our family, I sure am thankful each day for every single one of you and what you bring to our lives. Can't wait to see each of you and your precious children next month!

Some of our BTHS boys and young men at BSF's 2008 Conference (along with a couple of our sibs who took advantage of the photo op!
(Photo courtesy of Amanda Clark~2008)

2010 Conference Overview

Renaissance at SeaWorld, Orlando, Florida

July 26 - 31, 2010

Don't miss this opportunity! If you haven't already, please register with BSF via our website (www.barthsyndrome.org) and reserve your room at the Renaissance. Online and phone reservations at Renaissance at SeaWorld will be accepted. The Renaissance is offering a room rate of US $115 per night (plus taxes) until July 9, 2010. To reserve your room online, please visit the following link (https://resweb.passkey.com/Resweb.do?mode=welcome_ei_new&eventID=1482151). To reserve your room by telephone, please call Renaissance at SeaWorld (1-800-266-9432) and reference "Barth Syndrome Conference" when making your reservation to guarantee the reduced rate.

	Science & Medicine	**Family**
July 26, 2010		Welcome Reception
July 27–28, 2010	Barth Syndrome Clinic (doctors/physicians involved in BTHS research)	Barth Syndrome Clinic
July 28, 2010	Physician/Scientist Registration	
July 29–30, 2010	Scientific/Medical Sessions	
July 29—31, 2010		Family/BTHS Individual/Sibling Sessions
July 31, 2010	SMAB Meeting	Closing Ceremony

Photos taken at the Social Event at BSF's 2008 Conference

Diagnosis of Barth Syndrome Leads Family to Barth Syndrome Foundation

By Kristi, Mother of Newly Diagnosed Son, Richland, MS

Christopher was born April 25, 2008. At five days old, he was diagnosed with dilated cardiomyopathy and left ventricular noncompaction (DCM/LVNC). Within weeks, it was determined that if he was to survive, a heart transplant was needed. He was not responsive to the medicine offered. During the heart transplant process, a muscle biopsy was performed and determined inconclusive. My husband and I were both uncomfortable with the statistics of his survival and opted against the transplant. We believed in faith and the power of prayer. We wanted Christopher to have quality of life, no matter how short that might be. Forty-five days later, he came home from the hospital and was admitted into hospice.

We had genetic counseling and blood testing done on Christopher along the way, several tests, too complicated for me to understand. For many months there were no answers. In the meantime, we celebrated the joyous event of his first birthday. We have come to realize never to take our loved ones for granted. I cannot express how special it was for us to reach that day.

Christopher had a heart medication called Coreg introduced when he was 13 months old. I had done research and found the possibility for his heart function to improve if we added a Beta blocker. His cardiologist went along and within three months (September 2009) it was determined that his heart had unexpectedly improved so drastically that he was discharged from hospice. We believe that it was God's will for him to survive so much longer than the doctors ever expected. We could think about our son in terms of months and years instead of one day at a time.

I had actually come to terms with the fact that we didn't know what caused Christopher's heart condition. I was just happy that he was still alive.

In January of 2010, our geneticist, Dr. Omar Rahman called and sent my world spinning again. He informed us he believed he had found why Christopher had cardiomyopathy. The most recent lab work sent to Harvard had found a deletion of the *TAZ* gene. His first advice was the best he could have possibly given since he directed me to BSF.

They looked specifically for Barth syndrome (BTHS) being the cause because of Christopher's cardiomyopathy and the fact he has a first cousin having the diagnosis of myopathy. Jacob and Christopher both show characteristics of BTHS. Jacob is 9. We also just got confirmation of his diagnosis in April 2010.

The diagnosis of these boys has determined that my sister and I are carriers and that there is the possibility of others in my family being affected by BTHS.

I also have a maternal first cousin who has all BTHS clinical symptoms with the exception of cardiomyopathy. When his mother heard of BTHS she felt she had answers for the problems they dealt with back in the early 70's. Brian is now 37. His age could give all of us some hope. He has yet to be officially diagnosed. My mother had two brothers who passed before the age of 6 months, one from a heart condition and the other from pneumonia in the early 50's. BTHS wasn't discovered until much later. With as many cases as I believe there are in my family, however, this is just more proof of how much BTHS is severely underdiagnosed.

I am so glad that I found BSF! I was warmly welcomed into what is commonly referred to as a family. I see why the BSF is described as such. This overwhelming, mind boggling disease has a group of warm, caring, compassionate and INFORMED people. It is such a reassuring feeling to know there are others who have been exactly where we have been. We all have such a unique story, yet we all have such similar stories. I value the experience of a parent who has probably been in the same situation very much. I would trade a phone conversation with one of you to a resident in the ER who has never even heard of BTHS.

I wish for my family to attend BSF's upcoming Conference in July 2010 for a number of reasons. My doctor has a written letter of recommendation admitting that they cannot offer what is offered at the conference because of the lack of other affected individuals in our state. I intend to learn everything I can and after educating myself, sharing the BTHS information with the doctors in charge of Christopher's plan of care. I hope to get the emotional support offered to each individual of my family. I believe all of us need that very much.

BSF's Ambassadors—
Building Our Community One Donor at a Time!

By Stephen McCurdy, Chairman, Barth Syndrome Foundation

BSF has some of the most steadfast and loyal donors in the world. Over 725 donors contributed almost $700,000 in 2009 to help BSF continue on our mission. We received over 1,000 individual donations (some folks were inspired to donate more than once!) in a year that is being described as the Great Recession. BSF's total charitable contributions declined less than 5% in a year in which charities across the country reported serious fund raising challenges for the second year in a row.

Much of the credit must go to our equally intrepid fund raisers who understand that raising money for BSF is a very personal thing and for whom fund raising is really about community building. Steve and Jan Kugelmann have held their annual golf tournament for so many years that their friends and supporters call them to find out when the tournament is planned so that the weekend can be set aside. John and Liz Higgins's bowling night fund raiser continues to help pay for scientific research every year like clockwork. Rosemary Baffa and her kids have held so many bake sales that it is a wonder that the entire state of Pennsylvania is not in permanent carbo-load. And the Dunn family continues to entertain the neighborhood—this year with a cookout and Becky Chase performing in their back yard. Randy Buddemeyer and his business partner have also invited their many friends, colleagues and partner firms in the world of Florida real estate to join them each year for a golf tournament that raises funds jointly for Juvenile Diabetes and BSF. The tournament has grown larger, as have the total donations to BSF every year that Randy has held it, proving that despite the smaller wallets caused by the downturn in the real estate business, Randy's friends still have big hearts.

And our dear friend Gary Rodbell fielded the largest triathlon team yet, raising a record amount in 2009 and winning the Janus Charity Challenge and an additional $10,000 for BSF (not to mention a "personal best" in the Arizona Ironman). Gary and his various fund raising team-mates and friends have now raised $1 million for BSF since 2004 and substantially grown the number of people who are now familiar with Barth syndrome and our cause.

Others, like the Fairchilds, McCurdys, Sernels and Wilkins send out an annual letter to friends, family and colleagues providing an update on their own family and progress at BSF, further cementing the loyalty of these dedicated donors and strengthening the ties that bind our growing community together. Linda Stundis and Matt Toth both assisted in fund raising for BSF -- Linda, by applying for and winning a grant from a Boston foundation in support of the Barth Syndrome Medical Database and Biorepository, and Matt by applying to the National Institutes of Health for a grant to help fund the Scientific Sessions at the July Barth Syndrome Conference in Orlando, Florida. The "R-13" Grant was approved by the National Heart, Lung and Blood Institute and by the Office of Rare Disease Research. This was the second R-13 grant awarded by the NIH to BSF—the first was won by Dr. Richard Kelley for our 2008 Barth Syndrome Conference.

Together, these folks are BSF ambassadors, emissaries from the Barth syndrome community for the cause to which we are all so committed. Their efforts raise money and spread awareness of Barth syndrome, shining light on this rare disorder. But even more important, they help to build and strengthen our global community which is critically important to our mission and even our continued existence! By expanding awareness, we invariably find and then can help more families. More families bring more data, more clinical experiences and more opportunities for scientists and researchers to develop a deeper understanding of the causes of and improved treatments for Barth syndrome. Without these dedicated BSF ambassadors, most of you who are reading these words would not be a part of our family and our cause today… a loss I refuse to contemplate! And so, to all of our ambassadors today and all those of you who are inspired to don that mantle in the future, THANK YOU! Together, we create hope and confidence where there would otherwise be despair, community to replace loneliness, and futures to look forward to.

Barth Syndrome Clinical Data and Biological Specimens—BRR

By Katherine McCurdy, Board of Directors, Barth Syndrome Foundation

One substantial hurdle faced by many clinical researchers is to find and enlist the support of patients affected by the disease being studied. This is especially true for rare disorders. Gaining access to patients can be a daunting task, and gathering extensive, longitudinal data on each patient can be next to impossible. This is one of the reasons rare disorders are often called “orphan” diseases and attract little research attention.

With Barth syndrome, we have a significant advantage in that we have taken the last few years and invested time, expertise and money to create and develop the Barth Syndrome Registry and Biorepository (BRR). The data and samples in our BRR are legally owned and controlled by BSF but housed and operated for us by a major educational and research institution which serves as the “warehouse” for clinical data about those with Barth syndrome (data reported by families, retrieved directly from medical records or collected during the clinics at our international conferences). The BRR also contains biological samples, including DNA, various cell lines (lymphoblast lines made from blood samples and fibroblast lines created from skin samples) and a number of tissues from Barth patients such as hearts that have been removed during transplants and tissues that have been generously and selflessly donated at autopsy. Both the clinical data and the biological samples are extremely precious and are critical elements of our push toward more advanced clinical research and the development of therapies for Barth syndrome.

Several exciting developments have occurred recently that we want to share with you:

1. The BRR is being transferred from the University of Florida (UF) to the Children’s Hospital Boston (CHB). UF was a good partner as we set up this critical resource, but the move to CHB provides some real benefits. In Boston, Dr. Carolyn Spencer continues to be involved, and she has gained the attention of a number of new subspecialists as well. She also has brought in Dr. Amy Roberts as an additional Principal Investigator. Dr. Roberts is the Director of the Cardiovascular Genetics Research Program at CHB and runs the hospital’s main registry for children with heart disease. Families, physicians and researchers attending the July Barth conference will have a chance to meet her and benefit from her expertise. Already, we have seen positive differences in focus and increasing momentum with the BRR, and we are excited about the progress.

2. Significant financial support for the BRR at CHB has been won through two grants from donors in the Boston area—an anonymous foundation and a generous individual, Christopher McKown. We are very grateful to these donors who appreciate the value of a comprehensive BRR to Barth syndrome research.

3. More IRB-approved clinical data will be collected at this July’s conference than ever before. “IRB-approved” means that the researchers gathering data have been approved by their own Institutional Review Board to conduct specific, carefully designed and executed research of the highest scientific quality, ensuring protection of the individuals who participate. Importantly, it also means that the clinical data can be used in peer-reviewed scientific articles. This year, with so many research studies being conducted, families will need to spend a little extra time filling out necessary paperwork at the beginning of the clinics. Families who will participate in this year’s conference clinics will be hearing more details soon.

The real measure of success of a registry and/or biorepository is what it produces, and we are beginning to see some results. A handful of scientists from around the world have applied to use BTHS lymphoblast and fibroblast cell lines and are conducting research on them currently. Researchers are beginning to request clinical data as well. Most of those who have approached the BRR are scientists BSF knows, but some are new, and that is especially exciting. We can see that our strategy of making access to critical data and samples easier is drawing in more researchers and facilitating their work! At this July’s conference, we will get an initial look at some composite clinical information about Barth syndrome obtained from BRR data. Additionally, several papers, now in the publishing pipeline, will acknowledge the critical role of the BRR. And this is just the beginning.

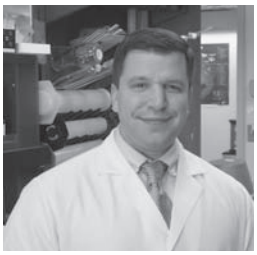
We strongly encourage all BTHS individuals to participate in the BRR, and we thank everyone who is already involved. You will have a direct, positive impact on scientific and medical advancement. We are extremely grateful for the growth and evolution of this critical asset and hopeful that it truly will facilitate the development of treatments and ultimately a cure for Barth syndrome.

Seven Grants Awarded for BSF's 2009 Research Grant Program

(Cont'd from page 1)

Zaza Khuchua, PhD
Research Associate Professor,
Children's Hospital Medical Center,
Cincinnati, OH
The shRNA-mediated tafazzin knockdown mouse model for Barth syndrome
Awarded—US $39,998 for 2 years

Dr. Khuchua proposes to continue his analysis of the characteristics (phenotype) of the tafazzin knockdown mouse—the mouse line that BSF contracted with TaconicArtemis of Cologne, Germany to produce. The goal is to determine if this mouse line resembles humans with Barth syndrome in regard to symptoms like cardiomyopathy (exercise intolerance, neutropenia, growth delay) and in regard to biochemistry like abnormal cardiolipin levels (organic aciduria, abnormal mitochondria, abnormal mitochondrial respiration, increased ROS production—complexes I, III, and V activities, supercomplex assembly, ANT activity). Dr. Khuchua has communicated preliminary results that show abnormal cardiolipin levels in at least 4 organs of the tafazzin knockdown mouse. A mouse model of Barth syndrome is an important tool to learn more about the disease and to test treatment ideas.



Michael A. Kiebish, PhD
Postdoctoral Research Associate,
Washington University School of Medicine, St. Louis, MO
Does cardiolipin synthase upregulation alleviate cardiolipin abnormalities and bioenergetic dysfunction in Barth syndrome?
Awarded—US $40,000 for 2 years

Dr. Kiebish proposes to analyze the characteristics (phenotype) of the tafazzin knockdown mouse line (supplied by BSF) and to concentrate on the changes in its lipid characteristics specifically using the "shotgun lipidomics" developed in this lab (sensitive analytical method that measures small quantities of different cardiolipin species). He intends to analyze the enzyme activities of the electron transport chain (complexes I through V) of these mice as well as to monitor the changes in heart cardiolipin. In addition, Dr. Kiebish intends to crossbreed the tafazzin knockdown mouse with a transgenic mouse line that overexpresses the human cardiolipin synthase gene (hCLS) and monitor for any changes in lipids or to see if the hCLS gene can reverse (suppress) the changes that the tafazzin gene knockdown causes. Interestingly, the hCLS transgenic line appears to have an increased heart fractional shortening. It is therapeutically useful to know if other genes can be recruited to alleviate the deficiencies caused by a defective tafazzin gene.

Miriam Greenberg, PhD
Professor and Associate Dean,
Wayne State University, Detroit, MI
Perturbation of mitophagy in cardiolipin mutants
Awarded—US $40,000 for 1 year
**Funds provided by BSTrust*

Dr. Greenberg has uncovered an interesting observation in at least two yeast strains that are mutated in genes that control cardiolipin synthesis—the pgs1 and cdrs1 genes. She found that when these genes are mutated, the yeast cell displays an abnormal (enlarged) vacuole, which is a subcellular organelle equivalent to the mammalian subcellular organelle called the lysosome. The lysosome is thought to be the "garbage disposal system" of the cell—the place where other subcellular organelles are disassembled and recycled for further use by the cell. These same cardiolipin mutants can be restored (suppressed) to a normal condition (wild-type) when certain genes involved in the turnover or recycling of mitochondria (mitophagy genes) are mutated or inactivated. Dr. Greenberg will determine if the tafazzin gene has similar properties to these other two genes.

The central idea is the discovery of a previously unknown genetic linkage between the mitochondria and the vacuole/lysosome. This linkage is evident when there are changes to the lipid cardiolipin—the lipid that is associated with Barth syndrome. This vacuole/lysosome connection with the mitochondria is relevant because there are several myopathy-associated genetic diseases (i.e. Pompe disease) that are known to have abnormal lysosomes. These results point to the possibility that some of the cardiac problems of Barth syndrome may not be exclusively associated with mitochondrial dysfunction as we have always thought. Dr. Greenberg postulates that altered lysosomal function (overactivity) can be involved with the cardiomyopathy seen in Barth syndrome, and this new observation may lead to different ways to consider looking for a treatment. The hypothesis thread is: 1) lysosomes are overactive in cardiolipin deficient mutants, 2) this causes an increase in mitophagy or loss of mitochondria via the lysosome, 3) some of the pathophysiology of Barth syndrome may arise from this increased mitophagy, and 4) decreasing mitophagy may useful for treating Barth syndrome individuals.

(Cont'd on page 13)

(Cont'd from page 12)

Yang Xu, PhD, MD
Instructor, New York University School of Medicine, New York, NY
Expression levels, localization, and function of tafazzin isoforms
Awarded—US $38,370 for 1 year

Dr. Xu proposes to use the newly developed antibodies (in collaboration with Dr. Steven Claypool) made against human tafazzin protein to gain insight into the nature of the types of tafazzin protein found in all mammalian tissues. Currently we have no tool to visualize the tafazzin protein that is present naturally in human cells, and simple observations of the native (endogenous) tafazzin protein (Western blots) could reveal important information or suggest new hypotheses. For example, we know that human cells produce a tafazzin mRNA that is shorter than the predicted full length (exon 5 deletion)—does this shortened tafazzin mRNA (isoform) correspond to a smaller tafazzin protein? Dr. Xu intends to identify the different forms of the tafazzin protein (isoforms) that are present in different human cell lines and human tissues (including Barth syndrome), to determine the intramitochondrial location of these isoforms, and to determine the functional differences (enzymatic) if any, between these isoforms. Dr. Xu has already provided data that show the value of these antibodies by detecting endogenous tafazzin protein in human cell lines and the absence of this protein in several Barth syndrome cell lines.

W. Todd Cade, PT, PhD
Assistant Professor, Washington University School of Medicine, St. Louis, MO
Safety and efficacy of aerobic exercise training in Barth syndrome: a pilot study
Awarded—US $39,600 for 2 years

Dr. Cade's clinical project is designed to determine the value of 12 weeks of supervised aerobic exercise training (cardiovascular rehabilitation) in Barth syndrome individuals. The plan is to monitor the participant's exercise performance before (most conveniently done at the BSF Conference in July, 2010) and after the supervised exercise program. From past BSF Conferences, Dr. Cade and colleagues have measured several physiological indices of Barth syndrome individuals: their exercise limitations, fatigue levels, whole body oxygen consumption, cardiac performance, and skeletal muscle tissue extraction/utilization. We know that older patients with various cardiac problems show a real benefit with this type of exercise training. The hypothesis here is to find out if the same types of benefits seen in other cardiac patients are transferable to Barth syndrome individuals. Should this project demonstrate a real benefit with aerobic training, it may form the basis of a clinical recommendation for treatment.

Grant Hatch, PhD
Professor, University of Manitoba, Winnipeg, Manitoba, Canada
Role of human monolyso-cardiolipin acyltransferase in Barth syndrome
Awarded—US $40,000 for 1 year
**Funds provided by BSF Canada*

Dr. Hatch proposes to extend his work on the newly discovered and recently published human enzyme MLCL AT1 (monolyso-cardiolipin acyltransferase) to determine if it can substitute for tafazzin function in several Barth syndrome cell lines (lymphoblasts). Specifically, several cell lines from Barth syndrome individuals who differ in severity of their disease will be transformed with the human MLCL AT1 mini-gene. Dr. Hatch will determine if cardiolipin levels and mitochondrial energy production have returned to normal (wild-type) levels. He will also determine if the endogenous levels of MLCL AT1 in these same cell lines can be correlated with the disease severity. Preliminary experiments have shown that this mini-gene does elevate the cardiolipin levels in one Barth syndrome lymphoblast line and may restore some of the mitochondrial function. This avenue of investigation could serve as an alternate therapeutic approach. If we can find a way to increase MLCL AT1 expression in tafazzin deficient cells, it may ameliorate some of the symptoms of Barth syndrome.

William Pu, MD
Associate Professor, Children's Hospital of Boston, Boston, MA
Analysis of metabolic abnormalities in TAZ-deficient cardiomyocytes
Awarded—US $40,000 for 1 year

Dr. Pu is proposing to develop two mammalian cellular models of tafazzin-deficient cardiomyocytes to study the effects on the citric acid cycle—the abnormality that Dr. Richard Kelley has proposed to be at the center of the pathophysiology of Barth syndrome. In the first model, he will make a shRNA-knockdown construct (adenovirus vector) in rat ventricular cardiomyocytes. In the second model, he will use the relatively new technology of induced pluripotent stem cells (iPSC) by taking fibroblasts from skin biopsies of Barth syndrome individuals and deriving cardiomyocytes using a series of genetic transformations. These cellular model systems will be analyzed for their citric acid cycle function and other mitochondrial properties using gas chromatography-mass spectrometry (GC-MS) and various radiolabelled tracer compounds. These experiments could validate the idea that abnormalities in the citric acid cycle are connected with Barth syndrome, and they may lead to new ways to find therapeutic compounds or provide a method to monitor a specific treatment.

Awareness of Barth Syndrome is Growing Exponentially

There has been a significant increase in Barth syndrome related peer-reviewed journal articles published. To date, there have been **50** articles published on research conducted with the support of BSF and/or BSF affiliate funding (denoted below with an asterick**).** Listed below are articles relevant to BTHS that have been added to BSF's library since the last issue of the Barth Syndrome Journal. To view the complete bibliography on Barth syndrome, please visit www.barthsyndrome.org.

1. Rijken PJ. **Phosphatidylcholine-protein interactions and remodeling of cardiolipin in yeast mitochondria.** Doctoral Thesis, Scheikunde Proefschriften, 2010*
2. Osman C, Haag M, Wieland FT, Brügger B, Langer T. **A mitochondrial phosphatase required for cardiolipin biosynthesis: the PGP phosphatase Gep4.** EMBO J. 2010 May 18. [Epub ahead of print]
3. Xu FY, McBride H, Acehan D, Vaz FM, Houtkooper RH, Lee RM, Mowat MA, Hatch GM. **The dynamics of cardiolipin synthesis post mitochondrial fusion.** Biochim Biophys Acta. 2010 Apr 28. [Epub ahead of print]*
4. Kiebish MA, Bell R, Yang K, Phan T, Zhao Z, Ames W, Seyfried TN, Gross RW, Chuang JH, Han X. **Dynamic simulation of cardiolipin remodeling: Greasing the wheels for an interpretative approach to lipidomics.** J Lipid Res. 2010 Apr 21. [Epub ahead of print]
5. Towbin JA, Sleeper L, Jefferies JL, Colan S, Webber SA, Canter CE, Hsu DT, Ware SM, Wilkinson JD, Orav EJ, Lipshultz SE. **Genetic and Viral Genome Analysis of Childhood Cardiomyopathy: The PCMR/PCSR Experience** [abstract]. In American College of Cardiology 59th Annual Scientific Session; 2010 Mar 14-16; Altanta, GA: J. Am. Coll. Cardiol. 2010;55;A43.E409.
6. Macchioni L, Corazzi T, Davidescu M, Francescangeli E, Roberti R, Corazzi L. **Cytochrome c redox state influences the binding and release of cytochrome c in model membranes and in brain mitochondria.** Mol Cell Biochem. 2010 Mar 30. [Epub ahead of print]
7. Raja M. **The Role of Phosphatidic Acid and Cardiolipin in Stability of the Tetrameric Assembly of Potassium Channel KcsA.** J Membr Biol. 2010 Mar 30. [Epub ahead of print]
8. Parikh S, Saneto R, Falk MJ, Anselm I, Cohen BH, Haas R, Medicine Society TM. **A modern approach to the treatment of mitochondrial disease.** Curr Treat Options Neurol. 2009 Nov;11(6):414-30.
9. He Q. **Tafazzin knockdown causes hypertrophy of neonatal ventricular myocytes.** Am J Physiol Heart Circ Physiol. 2010 Mar 26. [Epub ahead of print].*
10. Chang B, Momoi N, Shan L, Mitomo M, Aoyagi Y, Endo K, Takeda I, Chen R, Xing Y, Yu X, Watanabe S, Yoshida T, Kanegane H, Tsubata S, Bowles NE, Ichida F, Miyawaki T; Noncompaction study collaborators. **Gonadal mosaicism of a *TAZ* (G4.5) mutation in a Japanese family with Barth syndrome and left ventricular noncompaction.** Mol Genet Metab. 2010 Mar 2. [Epub ahead of print]
11. Jefferies JL, Towbin JA. **Dilated cardiomyopathy.** Lancet. 2010 Feb 27;375(9716):752-62.
12. Gonzalvez F, Pariselli F, Jalmar O, Dupaigne P, Sureau F, Dellinger M, Hendrickson EA, Bernard S, Petit PX. **Mechanistic Issues of the Interaction of the Hairpin-Forming Domain of tBid with Mitochondrial Cardiolipin.** PLoS One. 2010 Feb 22;5(2):e9342.
13. Wiswedel I, Gardemann A, Storch A, Peter D, Schild L. **Degradation of phospholipids by oxidative stress-exceptional significance of cardiolipin.** Free Radic Res. 2010 Feb;44(2):135-45.
14. Corcelli A, Saponetti MS, Zaccagnino P, Lopalco P, Mastrodonato MG, Liquori GE, Lorusso M. **Mitochondria isolated in nearly isotonic KCl buffer: Focus on cardiolipin and organelle morphology.** Biochim Biophys Acta. 2010 Jan 20. [Epub ahead of print]
15. Chen S, Liu D, Finley RL Jr, Greenberg ML. **Loss of mitochondrial DNA in the yeast cardiolipin synthase crd1 mutant leads to up-regulation of the protein kinase Swe1p that regulates the G2/M transition.** J Biol Chem. 2010 Jan 19. [Epub ahead of print]
16. Orstavik KH. **X chromosome inactivation in clinical practice.** Hum Genet. 2009 Sep;126(3):363-73. Epub 2009 Apr 25. Review.
17. Nie J, Hao X, Chen D, Han X, Chang Z, Shi Y. **A novel function of the human CLS1 in phosphatidylglycerol synthesis and remodeling.** Biochim Biophys Acta. 2009 Dec 16. [Epub ahead of print]
18. Cosson L, Toutain A, Simard G, Paoli F, Kulik W, Vaz FM, Blasco H, Chantepie A, Labarthe F. **Barth syndrome in a female patient** [Abstract]. In the 11th International Congress of Inborn Errors of Metabolism Meeting, October 2009. Molecular Genetics and Metabolism 98, Issue 1 p. 89-118.
19. Kutik S, Rissler M, Guan XL, Guiard B, Shui G, Gebert N, Heacock PN, Rehling P, Dowhan W, Wenk MR, Pfanner N, Wiedemann N. **The translocator maintenance protein Tam41 is required for mitochondrial cardiolipin biosynthesis.** J Cell Biol. 2008 Dec 29;183(7):1213-21.
20. Jackson SK, Abate W, Tonks AJ. **Lysophospholipid acyltransferases: Novel potential regulators of the inflammatory response and target for new drug discovery.** Pharmacol Ther. 2008 Jul;119(1):104-14. Epub 2008 Apr 23. Review.

Research Initiatives Relevant to Barth Syndrome

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

National Institute of Health (NIH)

Natural History of Disorders Identifiable by Newborn Screening (R01) (RFA-HD-10-019) Eunice Kennedy Shriver National Institute of Child Health and Human Development	Application Receipt Date(s): August 03, 2010 http://grants.nih.gov/grants/guide/rfa-files/RFA-HD-10-019.html

Purpose: To develop a comprehensive understanding of the natural history of disorders that are currently identified by NBS or could potentially benefit from early identification by newborn screening. In addition, for some disorders, specific genotype-phenotype correlations may allow prediction of the clinical course, and for other disorders, identification of modifying genetic, epigenetic, or environmental factors will enhance an understanding of the clinical outcomes for an individual with such a condition.

NIAMS Small Grant Program For New Investigators (R03) Program Announcement (PAR) Number: PAR-09-031	Opening Date: January 23, 2009 Application Receipt/Submission Date(s): Multiple dates Expiration Date: October 25, 2011 http://grants.nih.gov/grants/guide/pa-files/PAR-09-031.html

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

Pilot and Feasibility Clinical Research Grants in Diabetes, Endocrine and Metabolic Diseases (R21) Program Announcement (PA) Number: PA-09-133)	Opening Date: May 16, 2009 Letters of Intent Receipt Date(s): N/A Application Receipt/Submission Date(s): Multiple dates Expiration Date: May 8, 2012 http://grants.nih.gov/grants/guide/pa-files/PA-09-133.html

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

American Society of Hematology

Patient Group Research Grant Opportunities

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

Children's Cardiomyopathy Foundation

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

United Mitochondrial Disease Foundation

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

Linda Stundis Leaves BSF

The Barth Syndrome Foundation ("BSF") announces that Linda Stundis will be leaving her role as Executive Director of the Barth Syndrome Foundation. The Board of BSF is grateful to her for her contributions over the last two years.

Linda came to BSF after many years of work with non-profits of various sizes, from Harvard Medical School and Brigham and Women's Hospital to the Treehouse Foundation in western Massachusetts, a small organization dedicated to improving the lives of foster children. During her tenure with us, Linda's key accomplishments included playing a leadership role in moving the BRR forward, facilitating the finalization of our Canadian affiliate licensing agreement, and ensuring that the Barth Syndrome Foundation was compliant with the standards of both the Better Business Bureau and the National Health Council, two organizations whose endorsement is important to potential funders. In addition, she recently secured a major grant for the Barth Syndrome Medical Database & Biorepository, Conference sponsorships, and important in-kind donations for the 2010 Conference.

The board has created a subcommittee to discuss how best to meet BSF's administrative and fund raising needs going forward. This small group, chaired by BSF Board Chairman Steve McCurdy, will work to define the skills that we will be seeking for a new management team. In the interim, the reporting structure will return largely to its former pattern: Science Director Matt Toth and Executive Assistant Lynda Sedefian will report to Kate McCurdy. President Shelley Bowen will continue to lead the 2010 conference with co-chair Jan Kugelmann and the many volunteers who make this event so successful every two years!

We know that you join us in thanking Linda Stundis and in wishing her every success in the future.

Have You Moved Lately?
Please Help Us Keep Your Information Current

In the past, the Post Office notified us of address changes. However, with so few actual mail pieces being sent during the year, we will not know you have moved unless you tell us. If your telephone number and/or e-mail address has changed, please let us know. If we do not have your e-mail address, please go online to add it to your contact information.

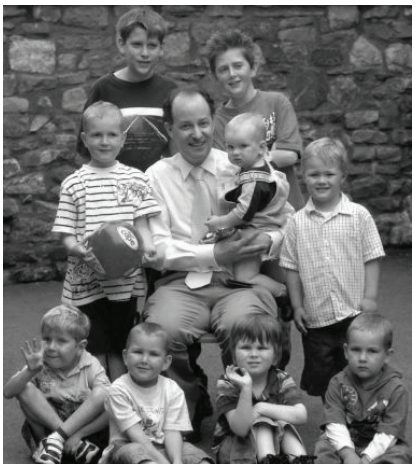
Barth families, if you think any information on your family might be incorrect, please be sure to update us.

Visit BSF's website and complete the 'Update Contact Information' form (http://www.barthsyndrome.org/english/View.asp?x=1568) that can be found under 'Families/Update Contact Information.' Thanks in advance for helping us "keep house."

Barth Syndrome Trust

A momentous milestone for Barth syndrome in the UK and Europe

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



Early days: Dr Steward and boys at the 2005 clinic.

Doctors at the Bristol Royal Hospital for Children and BST, working together, have been successful in obtaining funding from the National Health Service (NHS) for a Barth Syndrome Service. This funding is an endorsement of the importance of the Bristol Clinic which has been a vital resource for UK families since its inception in 2004. It will allow us to extend and improve the Clinic, as well as provide additional services for affected families. This new service will directly benefit patients in the UK and Europe. Looking further afield, through the collection of knowledge it will afford, it will also help every single person affected by Barth syndrome, regardless of where they live. It is a victory for our whole community.

It's difficult to express the magnitude of the achievement of the new Barth syndrome service; after all, for most UK families, there has been a volunteer-led clinic in existence for a number of years. For a newly-diagnosed family now, the journey ahead has become so much clearer than it was 10 years ago.

But the danger always lurked close by—the clinic and service available to our families was based purely on the goodwill of several key people and whilst we could always rely on their dedication, the reality was that, without these key people and the proper resources, we could quickly be in the same position we were in ten years ago when there was no clinic and no service available.

And so, this became our top priority: making sure that our boys and young men and all those to follow have access to the best care with the resources needed to deliver it. And the only way to do that was to bring our rare condition to the attention of the National Health Service and to plead our case and request a fully recognised service that could create a permanent "home" for our Barth families.

Now I need to ask each and every family in Europe (including UK) for help. For, if we are to succeed and prove that this service and all the money poured into it is worthwhile in our fight to save our boys, then the only way we can do it is if you use the service. Please clear your calendar and make your plans to join us in Bristol on the 24th—25th September 2010 for the first ever NHS clinic which will be the greatest milestone in our journey to date!

Talking of journeys, we know how difficult it can be to get to these clinics. Some families have to travel long distances, take time off school, college or work. For this reason, the BST trustees voted unanimously to create a new policy to help families with travel costs and we'll be telling you more about this new initiative soon. Our special thanks go to our fundraisers without whom this would not be possible. Everyone has had a special part to play in this success and we are grateful to everyone who has invested their time and resources into this project.

I am always aware that Barth syndrome knows no boundaries and that we serve our families in the whole of Europe too. For this reason, we were thrilled to learn that all families from the EU have the right of access to the Barth syndrome service, if such a service does not exist in their own region. All you need is a signed E112 form which you can obtain from your country's health service. You are all very welcome and we look forward with great anticipation to seeing you in September.

Families in UK and Europe - Save the Date!

24th – 25th September 2010

NHS Barth Syndrome Clinic

Bristol Royal Hospital for Children,
the centre of expertise for Barth syndrome

An opportunity not to be missed.
To register please contact BST on info@barthsyndrome.org.uk or barthsyndromeservice@uhbristol.nhs.uk

New NHS Service for UK & Europe

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

Dr Bev Tsai-Goodman presenting at the 2009 clinic.

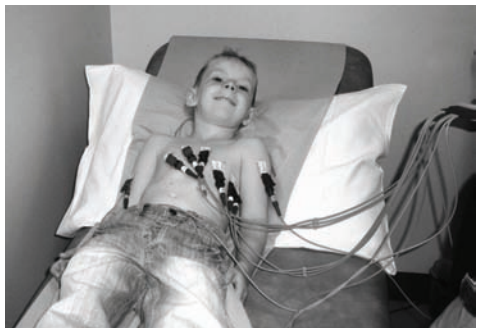
Just before Christmas Drs Colin Steward, Bev Tsai-Goodman and Ruth Newbury-Ecob at the Bristol Royal Hospital for Children (BRCH) received momentous news: the Minister for Health had approved the establishment of a national service for Barth syndrome in the UK for the next five years. The seed of this development began with a conversation between Michaela Damin and the Chairman of the National Commissioning Group (NCG) of the NHS several years ago. Michaela then persuaded Colin and his colleagues to put together a proposal to make the annual Barth clinic, established between BST and BRCH eight years ago, the hub of a year round, patient-centred service.

The service that we proposed after much discussion and which is now being implemented in stages is as follows:

- Protected clinical time for Colin and Bev to oversee the service and concentrate on public and professional awareness of the disease;
- A half-time Clinical Nurse Practitioner (to act as the central link person, capable of travelling to families and schools, organising the annual clinic and educating nurses) and dietician (to concentrate on dietary advice, prevention of hypoglycaemia and dietician education and liaison);
- G-CSF for all boys that need it, including home training in injection technique and deliveries of drug to patients' homes;
- Free biochemical and genetic testing for patients in at-risk groups;
- Dedicated genetic input from Ruth and her colleagues, from echo technicians, a clinical psychologist, physiotherapist, occupational therapist, speech and language specialist, and Consultants in Metabolic Medicine, Neurology, Gastroenterology, Endocrinology and adult transitional cardiac care;
- More sophisticated and patient-appropriate testing;
- A facility for patients from hospitals lacking relevant expertise across the European Union (via E112 forms).

Our first application went in almost 18 months ago and the service officially began on April 1, 2010. Contracts are currently being negotiated, posts advertised and interviews arranged, and Colin, Bev and Michaela hope to have the whole team in place by the summer. There is no doubt that there will be many challenges along the way: getting doctors to appreciate that they must know about and look out for this disease, organising care in partnership with doctors and allied professionals in other teaching and district hospitals, and servicing families across long distances to mention just a few. If, in five years, most paediatricians know about the disease, protocols are available for all major areas of management and families are more satisfied with care (and visit hospital less often!) we should be able to look back with pride. For now there is much to be done, but Barth syndrome has perhaps gained its greatest foothold yet in wider recognition by health professionals.

A day at the clinic: Medical checks, Play Therapy and Educational Sessions.



Barth Syndrome Trust—Family Page

Action-man, Michael

My name is Michael. I am 10 years old. I live in Scotland with my mum and dad, I have a dog called Ben. My hobbies are golf, swimming and playing my PS3 and Wii. We live in a town by the sea and I like to go for walks on the beach with Ben. My favourite holiday destination is Centre Parcs, I go there with my parents and my cousin Brogan. My favourite activity on holiday is going on the quad bikes.

Helping a Grandson Live Life to the Full

By Linda Barratt

Linda and John with grandson, Dillon, age 5.
(Photos courtesy BSTrust ~ 2010)

Julie and Scott phoned to say they had a son named Dillon. They also said he was in intensive care with breathing problems, but not to worry as it was only a precaution. That was only the beginning. Dillon had to be transferred to Leeds, as the local hospital did not have the facilities to care for him. We were told that he had a major infection and the next 24 hours would be critical. I spent hours watching my grandson fight for his life.

When he was 4 days old, they told Julie and Scott he would have to have a heart transplant. It was a nightmare because they didn't have enough answers as to what caused his problems. During the next 10 weeks Dillon had every test possible.

Then we brought Dillon home. It still took many months for him to be correctly diagnosed with Barth syndrome. We all had mixed feelings, but at least now we knew what it was. After a year he was taking no medicine, and was taken off the transplant list. They said he may still have to have a heart transplant at some time, but while his heart was improving, to leave it alone.

Dillon always has to be busy and loves everything he does. At his nursery they moved him up early, because he was so active. Now he is at school and loves it. Is he tired? Far from it—as soon as school is over, he pesters his uncle Phil to take him to feed the calves. He loves gardening with both his granddads, pets, reading, animals, sledging, snowballing, swimming, and flirting with the girls. In fact, he loves everything he does, except going to bed and is an expert in delaying tactics.

Grandparents: One of the happiest times of your life is when your first grandchild is born. But everything is turned upside down when the child is taken into intensive care. There is the wait for diagnosis, not really knowing what is happening, and watching your grandchild fight for life. You keep wondering why is this happening to your family. It's very hard to come to terms with it, not knowing what to do, or how to help, thinking, 'How shall we cope?' I can assure you—you will.

The first few months are extremely hard for all the family, waiting for answers, until they get the correct diagnosis. It affects people in different ways. I wanted to hold Dillon all the time, but my husband would not, because he was afraid of getting too close. Now they are inseparable. Dillon has a special bond with all his grandparents and his great grandma, Liz.

Luckily, Julie and Scott were put in touch with the Barth Syndrome Trust. They were there to help her through and were able to answer questions in layman's terms. They have been a lifeline, a Godsend.

(Cont'd on page 20)

(Cont'd from page 19)

For all grandparents it's especially hard. My advice to UK grandparents would be to go to the annual clinic at the Bristol Royal Hospital for Children and see the work they do and meet the other families. When I first went to the clinic and met the UK boys, they all seemed very happy. Go into the lecture which is very informative. I didn't understand the medical jargon fully, but then I didn't have to. All you need to learn is the basics.

We have a lot of praise for Leeds General Hospital and for all who work for the Barth Syndrome Trust and for the doctors and nurses in Bristol. Also we thank the helpers who work to raise money for the Trust.

So, Grandparents, enjoy your grandchild. You will have many happy times. Help him live life to the full, and you will reap the rewards.

Families at 2009 clinic.

Game, set and funds raised.

Teatime at the BST Tennis Tournament.

Fundraising

Thank you to our friends and families

Thank you for all the donations received since the last newsletter. Fundraising has continued without a break, with resourceful friends, colleagues and family arranging a variety of events:

Basingstoke Area

Terri Allison, our Basingstoke area fundraising co-ordinator writes:

Here in the Basingstoke area we are still soldiering on with various fundraisers.

The annual BST tennis tournament in Oakley, is still going well and attracting regular friends and players, raising £355 in April.

Heather and Richard Oram, with the help of Terri Allison and Anne and Barry Ward, and friends from the village, have been running quizzes each year in Overton and this year raised £587.

We've also had the takings of another quiz donated to us as the winners' charity of their choice. Our grateful thanks to them for £300.

(Cont'd on page 21)

(Cont'd from page 20)

Bat and Ball Club

My dear friend Sarah Whithorn (another of our fundraising volunteers) and I play for the 'Bat and Ball' table tennis team in a tournament in the Channel Islands every year. It is the tradition on the last evening in the bar, to 'fine' all players for the most outrageous of reasons. This causes lots of laughter and shouts of denial at some of the 'accusations' of 'wrong doing or mishap'. The money was always donated to a random charity, however this wonderful bunch of people have chosen BST as their charity and for the past four years we have received an ever growing amount. This year it was £187.50. Considering this is only from a dozen or so people putting in the 'pot', it's a reflection of their generosity and friendship to the Trust. Heartfelt thanks to them all.

Dancing the Night Away

In April, Maggie Donovan organised a ball in Whitchurch, Hampshire. Generous supporters came along on the night, bringing their own food, drink, crockery and cutlery. They then put their hands in their pockets again to buy raffle tickets. They listened and danced to a great band (thank you Hoi Polloi – the magic lives on!) who put up a bottle of Moet for a prize to the person who guessed the average age of the band. (Sh!!) £903 was raised specifically to help UK families to travel to the new Clinic. Thank you Maggie and friends.

Sponsored Walk

Laura Brown and her daughter, Katie again walked part of the Test Way to raise £138. They are inspired by a young friend of Katie's who has Barth syndrome.

Derbyshire Dales Fundraiser

Derbyshire Dales and District Council raised over £315 which included proceeds from a book sale, bacon butty sale and raffle by the Revenues and IT section. Thank you also to the Tourist Information Offices in Ashbourne and Matlock for displaying our collection boxes. Their inspiration is also a young lad with Barth syndrome.

Fireworks

BST was the charity chosen by the Friends Therapeutic Community Trust of Shudy Camps, near Cambridge, to receive entry donations of £200 from a Fireworks Display in November of last year. Thank you for thinking of us.

In Memory

Westgate School in Otley held a beetle drive in memory of their young pupil, Philip Brown. They raised £262.64. His parents, Alan and Maike, and his childminder, Claire Clements, held another fundraiser in Philip's memory in January, collecting an incredible £1,163 for the Trust.

Waitrose Community Matters

£640 was received from Waitrose supermarket in Romsey, Hampshire. Under its Community Matters scheme, £1,000 is distributed between three local projects each month. Thank you to Romsey's Waitrose customers for voting for BST in February.

Other Donations

Adam Reddin for raffling a signed Bristol Rovers shirt - £200
E-tecture, Germany - £268

A number of personal donations and monthly standing orders have been received since our last newsletter. Please see the back pages for a full list of names. Our very grateful thanks to all our donors for your generosity.

BST Receipts and Payments Accounts

Year	31 Dec 2009	31 Dec 2008
Receipts	£33,084	£13,825
Payments	£31,794	£ 8,116
Net	£ 1,290	£ 5,709
Cash funds year end	£43,806	£42,516

Barth Syndrome Foundation of Canada

Embarking on an exciting focus for 2010

By Lynn Elwood, President, Barth Syndrome Foundation of Canada

Another successful BSFCa Annual General Meeting.

Looking back at 2009 it was quite a successful year. During this challenging time we received a high level of support from our donors and we were successful in managing program expenditures so that we maintained a balanced budget and closed the year in a strong financial position. See our financial statement for details. We achieved major program goals and have started 2010 in a strong position to deliver on our new program plans.

In our 2010 planning session with the Executive and the Board, we took a fresh look at our goals and objectives as an organization. The result is a new focus that we are all very excited about. We started by defining who our customers are.

Primary Customer	Affected people - in the organization, to some extent not in the organization
Secondary Customer	Families - parents, grandparents Siblings Other relatives and close friends Significant others Carriers
Supporting Customers	Donors Physicians/Scientists Volunteers

We agreed that we will focus on our primary and secondary customers with a view to helping them in both the short and long term. We reviewed our mission statement and concluded that we will be driven by a more focused mission:

Enhancing the lives and outcomes of Canadian individuals and families affected by Barth syndrome.

As a result of this new mission we have altered plans to focus on our primary and secondary customers. We have an increased set of goals within Family Services, and we will start this with gaining professional help to determine what our customers really need. In past, since our volunteers are close to affected people, we have made assumptions about what our customers need; we believe it is time to seek assistance to ensure we are clear on what their top needs are.

Family Services

This program is a main focus this year. We will conduct a needs assessment of our primary and secondary customers to determine what issues are most pressing for them and what the organization can do for them. We have some of our young volunteers working on ways to communicate better with the affected people.

We have had an outreach with our families in April along with our Annual General Meeting and will aim for another one if possible in the fall. It is wonderful when the families and affected guys are able to spend time together and we will encourage that through the conference and outreach gatherings.

We are researching methods to assist our affected people with their long term life success and to advocate for themselves. One of our volunteers has done an update on the Barth syndrome educational booklets to provide Canadian educational system information and we are expecting to be able to provide this to families this year.

(Cont'd on page 23)

(Cont'd from page 22)

Awareness
We are focusing a little less on some aspects of the awareness program this year in order to spend more time and resources on Family Services and Science & Medicine. We will continue to focus on physician awareness and education and are starting to see some benefits in some hospitals. We will also re-launch our website this spring.

Charity Support
Some local charities have found ways to provide personal programs that help their members; we will work with these groups to gain advice on how to create and deliver similar programs.

Science & Medicine
We are excited about plans and progress in this program this year. We planned to participate in funding of one grant this year and budgeted accordingly. After participating in the grant application review and feedback from the SMAB, the Canadian board decided to increase our grant funding so that we could fund a full grant this year. We are pleased to be providing complete funding for the grant entitled "The role of human monolysocardiolipin acyltransferase in Barth syndrome" submitted by Grant Hatch, University of Winnipeg.

We are also sponsoring three Canadian physicians and scientists to attend the BSF International Conference including one physician who is joining the Conference with a goal of helping in the diagnosis of an existing Canadian child. If we are able to we may provide further sponsorship of the Conference, but we will need to clarify budget to see what is possible.

Fundraising
During our planning session, one of the goals was to increase grassroots fundraising this year. We have been very lucky to retain and grow fundraising revenues through our regular fundraisers and there have been some great individual events held by supporters. The individual fundraisers help to grow awareness, expand our volunteer base, bring in revenue from some new sources, and they also are great fun. In 2009 one of our volunteers turned their birthday party into a fundraiser. This year they plan a street party with the same goal and we have others planning a draw, a restaurant donation program and a Seniors musical event has already donated their proceeds to us. This type of creative thinking together with ambitious people is providing growing numbers of friends and funds.

2009 Financial Summary
While we started 2009 with a great deal of trepidation, we ended with a bang. We were very successful in all of our fundraising endeavours, and we kept our expenses under control. We ended the year with a healthy bank balance, in expectation of being able to fund additional research, and enhance other programs in 2010.

Year Ending 31 December 2009		
Opening Balance		$66,388
Revenue (including donations and fundraising)	$64,065	
Research grant funding	$21,020	
Other expenses	$16,189	
Excess of Revenue over expenses and funding		$26,856
Closing Balance		$93,244

With this balance in mind, we were able to make some ambitious plans for 2010. For details, please see the beginning of this article on the previous page.

A New Canadian Barth Boy Zachary

International co-operation

In the last few months our efforts have been lucky enough to find and begin helping a new family in Canada. The team effort involved in this was so incredible that we wanted to share it. Matt Toth, the BSF Scientific Director, was the first to find a reference to a boy in Toronto who was diagnosed with Barth syndrome and was in the hospital waiting for a heart transplant. Matt got in touch with the Canadian group, assuming we knew this family. The next mail came in from Michaela Damin, Chairperson of the UK organization, also assuming we knew the family. We did not! We immediately let our Executive know and people started to reach out and get in touch with them. The family was on Facebook and Susan Hone was quickly able to reach them, introduce us and share the anesthetic guidelines that might soon be needed by Zachary. Meanwhile we let some of the other families know and a number of people were able to get in touch with the family and share their support.

About a week later, one of the Canadian volunteers contacted us to say that she had seen information on a local boy that had dilated cardiomyopathy and sounded like someone that might have Barth syndrome. The information she had did not contain the diagnosis, but she recognized the symptoms and reached out to us.

Since this time a number of the Canadian groups have met with the family, provided them with information and talked with them in person and on the Internet. This has been a terrific example of a team effort by a large group of people from around the world, to find and help a new family.

Marj and Les Promote BSF of Canada

Co-Editors Les Morris and Marj Bridger at BSFCa's 2010 AGM.

At a volunteer meeting just two years ago Les Morris commented that he would like to see more communication from the Barth Syndrome Foundation of Canada (BSFCa) to its volunteers, donors and supporters.

Marj Bridger at the same meeting suggested that some volunteers could team up to share complimentary skills for jobs needing doing.

Presto! It wasn't long before Marj and Les shared their skills and produced the first ever BSFCa Volunteer Newsletter. Their efforts produced a beautiful and colourful, information-packed issue.

Before the next issue it was decided by the Executive that this fine publication should become the Canadian Newsletter with a much wider circulation.

Canadian Newsletter

March 2010

Barth Syndrome Foundation of Canada

www.barthsyndrome.ca

Dear Readers,

People like you have made this newsletter possible. We hope that you enjoy reading every article. Included with this newsletter is our annual appeal letter. The result of this appeal is a significant source of funding for the organization. It is our hope that you will consider it carefully.

-Les Morris and Marjorie Bridger

Barth Syndrome Foundation of Canada
1550 Kingston Road, Suite 1429
Pickering, ON
L1V 6W9
(905) 426-9126

Reflections from the President

By Lynn Elwood

What a great year we had financially in 2009! During this challenging year we received a high level of support from you, our donors, and we were successful in managing program expenditures so that we maintained a balanced budget. We achieved major program goals and are in a strong position to start 2010 with our new program plans. Thank you to all of you for your continued support. We couldn't do it without you.

In our 2010 planning session with the Executive and the Board, we took a fresh look at our goals and objectives as an organization. The result is a new focus that we are all very excited about. We started by defining who our customers are.

Primary Customer	Affected people - in the organization and to some extent not in the organization	
Secondary Customer	- Families (parents, grandparents) - Other relatives and close friends - Significant others	- Siblings - Carriers
Supporting Customers	- Donors - Physicians/Scientists - Volunteers	

We agreed that we will focus on our primary and secondary customers with a view to helping them in both the short and longer term. We reviewed our aims and concluded that we will be driven by a more focused mission statement, which is:

Enhancing the lives and outcomes of Canadian individuals and families affected by Barth syndrome.

IN THIS ISSUE

IN OUR NEXT ISSUE

Marj and Les were up to the task as Co-Editors. They refined the format and included regular articles such as "What is Barth?" and "From the Heart" where volunteers tell their stories about work with the BSFCa.

The Canadian newsletter goes out to volunteers, families, donors, golfers and all types of supporters. It has been extremely well received. It is colourful, easy to read, only eight pages and always newsy! The newsletter is produced twice a year.

The last issue of March 2010 had our BSFCa annual appeal letter included with it and was mailed out to almost three hundred people. We sincerely thank Marj and Les for combining their complimentary skills to the benefit of the BSFCa. Some would say that the moral of the story here is to watch carefully what you say aloud at a volunteer meeting!

If you would like to receive an e-mail copy or a printed copy of future Canadian newsletters, please give the Editors your address (Les.morris@sympatico.ca; mbridger@rogers.com).

BSFCa Annual General Meeting

Another Success!

Our 5th Annual General Meeting and Outreach was held on Saturday, April 24, 2010 in Toronto, Ontario. Nineteen people attended, including all of our Board members and Executive, four special young men, our newsletter editors and some devoted volunteers.

President Lynn Elwood summarized the successes of the foundation over the past year and focused on the new direction BSFCa has embarked on. It was a very interactive group with many questions. The Board members each presented on the various program areas. Two of the exciting announcements were the addition of a new family to the group and the news that McMaster Children's Hospital in Hamilton, Ontario has added Barth syndrome to its 30 diseases/syndromes it tests for when a child presents with idiopathic cardiomyopathy.

Cathy Ritter, Vice President and Susan Hone, Secretary were both re-elected for additional two year terms.

One of the newsletter editors, Marj Bridger, talked about the Canadian newsletter and their plans for the next newsletter. She thanked everyone for the accolades received on the last newsletter. A special presentation was made to Les Morris to thank him for his catering service at the 2010 executive committee planning session. A special thank you also to Ian Morris and Jones DesLauriers Insurance Management Inc. for the donation of the meeting space for our AGM.

The outreach was held at Tuckers Restaurant following the AGM. Everyone who attended had a good time catching up with each other and long goodbyes were shared. The majority of the families hope to see each other at the BSF Conference in July.

BSFCa thanks Les for his delicious catering!

Travis (age 15) entertains the group!

David, father of Travis (age 15), together with Robert (age 24), Adam (age 20+) and Ryan (age 19).

Enjoying BSFCa outreach at Tuckers Restaurant.

BSFCa young BTHS men hamming it up for food!

Growing Older with Barth Syndrome and Learning To Advocate For Himself

AN INTERVIEW WITH ADAM, AGE 20

What was it like moving from Public School to High School?
Adam: I had to go to the Academic Resource room. I had to tell them what assignment I needed help with and what accommodations I needed. I told them I needed extra time on tests, extra study time and a scribe.

Did you need to speak with the teachers?
Adam: My Mother came in at the beginning of the term to talk with the teachers, but I had to talk with them as well. I had to make sure they understood what accommodations I needed and make sure I could get those accommodations.

What changed when you went to College?
Adam: The difference with College is that you are an adult and you are responsible for yourself. It is your responsibility to make sure you speak up for yourself and to find who you need to help you get the accommodations you are after. You are responsible for talking to your teachers if you need more time, or you have to make special arrangements because you are sick.

How about going to the doctor when you were living away from home at College?
Adam: At college I had to go to the doctor because I was very sick. I was responsible for myself to make sure that I got in to see a doctor when needed. I was worried because I wasn't sure what to say. I had to learn how to accurately describe what was wrong and what special considerations had to be made, medications I am on and what I can take. It was difficult and stressful, but once I got through it the first time it got easier.

My Mom sent me to college with a card that described the condition and my doctors. It helped when I talked with reception because it was easier to show them the card than need to describe everything. It had all the information they needed. I also took a pamphlet that I left with the doctor.

Adam's Mom: When in town we still take Adam to his doctor's appointments, but he decides how much involvement we should have in each given situation. At his most recent appointment, he went alone in to see the doctor and handled the full set of questions and issues directly with the doctor. He has come a long way and is now an adult who understands his limitations and is able to ask for assistance when he needs it.

Come Golf With Us!!!

Mark the Date

Monday, September 13, 2010

Sharon, Joanie, Jan, and Lois support BSFCa's 5th Annual Charity Golf Classic.

BSFCa has begun to gear up for this year's golf day! Our golf tournaments have been great days and have provided the BSFCa with profits to fund their many programs and research. This is truly a fun day for all types of golfers. The setting at Tangle Creek Golf Course is perfect, the food is fabulous, the prizes plentiful, the raffles and silent auction items always interesting and the comraderie bountiful.

Look at these avid, wonderful people who fly in from Florida each year to golf with us!! Consider golfing with us on Monday September 13, 2010. For a registration flyer please contact Lois Galbraith (lois.galbraith@sympatico.ca - 705.877.3159) or Cathy Ritter (critter@barthsyndrome.ca - 705.424.6854). See you on the links!

Sibling Spotlight

Featuring friends from around the globe

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

Name: Olivia

Age: 8

Where are you from? St. Louis, Missouri, USA

What are your hobbies? Watching movies, reading and dancing.

Affected siblings? Noah, 8

What do you like doing with your brother? I like playing outside, riding bicycles and swimming in the pool with Noah.

If you met someone who had just found out that their brother had Barth syndrome, what would you say to make them feel better? There are a lot of people who are working very hard to take good care of him.

What does the Barth Syndrome Foundation (BSF) mean to you? It makes me happy to have BSF and to be able to meet other families who are just like ours.

Name: Natasha

Age: 26

Where are you from? London, England

What are your hobbies? I like horse riding, walking, swimming and socialising with friends and family.

Affected sibling? Antony (16 years)

What do you like doing with your brother? Anything he wants to do really. I enjoy everything I do with my brother as I don't get to see him much but when I do see Antony he always makes me smile, he's so special. I guess my favourite thing to do with him would have to be playing on the PlayStation with him. He loves all of his car racing games!

If you met someone who had just found out that their brother had BTHS, what would you say to make them feel better? I would tell them about the support that there is (BST/BSF) and all the wonderful doctors/consultants and I would also offer to help in any way I could.

What does the Barth Syndrome Trust / Barth Syndrome Foundation (BST/BSF) mean to you? To me I feel like the BST/BSF is like one big family. Everyone shares their experiences and we all support each other through the good times and the bad. I feel that there is hope in finding a cure for Barth syndrome and I feel we wouldn't have the opportunity to have researchers look into Barth syndrome if it wasn't for the BST/ BSF. So well done to everyone involved!

Donations Made Easier

Donate via Check: Make check payable to **Barth Syndrome Foundation, P.O. Box 618, Larchmont, New York 10538**

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

Donate through Causes on Facebook: To date, BSF has 1,680 members on Causes on Facebook. Join us on our on-line social network (http://apps.facebook.com/causes/46297/15341902).

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

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

Power of Kindness

Donor categories are based upon the past 18 months of cumulative giving

Barth Syndrome Foundation

PAULA & WOODY VARNER FUND

Stars ($5,000+)
Dillon Foundation
Yanney, Michael & Dr. Gail

Angels ($1,000—$4,999)
Cheatham, Dr. John
Daugherty, Robert
Pittenger, Jim & Julie
Wilkins, Dr. Mike & Sue

General Contributions ($50—$999)
Acklie Charitable Foundation
Allman, Peter & Maureen
Allman, Tom & Jane
Basler, Dr. Rod & Debbie
Beynon, Dave & Liz
Bingham, Dr. Dave & Kathy
Brehm, Russell & Louise
Buckley, Les & Nancy
Burmeister, Charles & Marita
Campbell, Bob & Candy
Cheatham, Linda
Desmond, Jerry & Sally
Farrar, Doug & Shawn
Firestone, Dave & Jane
Gelber, Dr. Ben & Elaine
Haessler, John & Nancy
Hayes, Dorothy
Hedgecock, Norm & Debbie
Henricks, Dr. Bruce & Peggy
Hurlbut, Dr. Greg & Sheri
Kenyon, Barbara & Allan
Kiechel, Dr. Fred & Vivian
Lehr Family Trust
Lincoln Community Foundation
Linder, Dr. Max & Pat
Massengale, Dr. Martin & Ruth
Minnick, Gates & Daisy
Nelson, Scott & Teri
Norris, Dr. Mike & Mary
Olson, Loy & Julie
Osborne. Dr. Tom & Nancy
Otte, Rob & Carolyn
Raun, Robert & Eileen
Richards, Matt & Jessica
Roskens, Ronald & Lois
Roth, Dr. Bob & Marcia
Schwab, Dr. Ronald & Diane
Seaman, Andrew & Robyn Steely
Sonderegger, Ted & Mary Ann
Stohs, Dr. Gene & Kristen
Stuart, James & Susan
Stuckey, Dennis & Nancy
Tegt, Dr. Tom & Barb
The Kubly Family Foundation
Varner, Judy
Varner, Tom & Beth
Wiederspan, Mark & Jessica
Wilkins, Dr. Jerry
Wilkins, E. Joanne
Wilkins, Marilyn
Wilkins, Dr. Lee & Kristi

SCIENCE/MEDICINE FUND

Stars ($5,000+)
Anonymous
Blumenthal, Richard & Cynthia
Malkin, Peter & Isabel
Malkin, Scott & Laura
McCurdy, Steve & Kate
McKown, Christopher
Russell, Dr. Paul & Allene
Sernel, Marc & Tracy

Angels ($1,000—$4,999)
Fowler, David & Susan
Kirkland and Ellis Foundation
The Patricia & Clarke Bailey Foundation

General Contributions ($50—$999)
American Express Gift Matching
Bill and Melinda Gates Foundation
Witzani, Sonja & Gregor
Zehner, Jon & Carlyn

GENERAL FUND

Stars ($5,000+)
American Express Gift Matching
Barad, Seth & Amy
Cusack, Tom & Carrie
Janus Foundation
Lake City International Trucks, Inc.
Lummis, Marilyn
Lummis, William & Dossy
Pierson, Dr. Richard & Allene
Pietrini, Andrew & Lauri (The Lebensfeld Foundation)
Russell, Dr. Paul & Allene
Vaisman, Natan & Beth

Angels ($1,000—$4,999)
Alisberg, Andy & Susan
Alparo, Arlene
American Express PAC Match
Bowen, Michael & Shelley
Brody, D.W. & Tracy
Buddemeyer, Randy & Leslie
Buly, Dr. Robert
Cain, James & Rita
Cloud, Jody
Crowley, Peter & Gretchen
Davis, Martha
Dun & Bradstreet Corporation Foundation
Elizabeth Lummis Malkin Fund
Emily Mason Malkin Fund
Evoy, Larry & Sally
Fergasam Garment Industries Ltd.
Floyd, Ed & Julie
Susan & David Fowler Charitable Gift Foundation
Garcia, Linda
Geary, Ann
Glenn, William
Grose, Madison & Nora
Haines, Dr. Tom
Hart, Dana
Hechinger, Nancy
Heine, Timothy
Ingersoll, Ann
Isaac, Paul & Karen
Kearns, Richard & Katherine
Kennett, Marie & Frank
Kugelmann, Peter & Karen
Kugelmann, Steve & Jan
Kuhl, Phillip & Karen
Lake City Idealease, LLC
Lummis, Richard & Page
Malkin, Louisa
Malkin, Rebecca Swift
Michaud, Steven & Yoko
Minor, Walter & Eleanor
North Florida Regional Thyroid Ctr.
Osnos, Peter & Susan
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WHAT IS BARTH SYNDROME?

Barth syndrome (BTHS; OMIM #302060) is a rare, serious genetic disorder primarily affecting males. It is found worldwide and is caused by a mutation in the tafazzin gene (*TAZ*, also called G4.5), resulting in an inborn error of lipid metabolism. Though not always present, cardinal characteristics of this multisystem disorder often include combinations and varying degrees of:

Photo courtesy of Amanda Clark ~ 2006

Cardiomyopathy
(usually dilated with variable myocardial hypertrophy and sometimes with left ventricular noncompaction and/or endocardial fibroelastosis)

Neutropenia
(chronic, cyclic, or intermittent)

Under-developed skeletal musculature and muscle weakness

Growth delay
(growth pattern similar to but often more severe than constitutional growth delay)

Exercise intolerance

3-methylglutaconic aciduria
(typically 5 to 20-fold increased)

Cardiolipin abnormalities
(though currently, this can be analyzed only in a research setting)

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