



**Barth Syndrome
Foundation**
www.barthsyndrome.org

Barth Syndrome Journal

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Fall 2009/Winter 2010

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

5th International Scientific, Medical and Family Conference Join Us in Celebrating BSF's 10th Anniversary! Change of Location

Renaissance at SeaWorld, Orlando, Florida July 26—31, 2010

By Linda Stundis, Executive Director, Barth Syndrome Foundation

Family Sessions (for Scientific Sessions please see page 7)

As hopefully everyone knows by now, the location for the 2010 Conference has been changed from Panama City Beach to the Renaissance at SeaWorld in Orlando, Florida.



We were concerned that the uncertainties associated with the new International Airport under construction in the previous location could have resulted in continuing high airfares and limited flight schedules and therefore would have had a detrimental impact on the ability of many to attend the Conference. (Cont'd on page 5)

Highlights of BTHS Clinical Data Meeting

By Carolyn Spencer, MD, Associate in Cardiology, Children's Hospital Boston; Assistant Professor in Pediatrics, Harvard Medical School, Boston, MA; Co-Principal Investigator, Barth Syndrome Medical Database & BioRepository

On September 29, 2009, a meeting was held in Boston, MA among a small group of experts who had collected clinical data at the 2008 Conference Clinic to discuss these data and their implications. In attendance were Drs. Richard Kelley, Carolyn Spencer, and Todd Cade; Dr. Paul Benni who developed the device used at the 2008 clinic to measure muscle oxygen saturation; and several physicians/researchers from Children's Hospital, Boston. Also in attendance were Linda Stundis, BSF Executive Director, Matt Toth, BSF Science Director, and Kate McCurdy, BSF Board member.

There were several interesting findings from the 2008 data that are helping to shed light on the symptoms suffered by Barth syndrome (BTHS) individuals. Many of the difficulties faced by BTHS individuals may be due to the inability of muscle tissue to use its energy-producing molecules properly, which results in a disruption of the fundamental processes of metabolism that takes place in the mitochondria. These findings will be the subject of further discussion at BSF's Scientific and Medical Advisory Board's meeting in December 2009 and then will be submitted to an appropriate journal for publication. (Cont'd on page 8)

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Words From Our President

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



Michael J. Bowen, Jr.
December 7, 1986—December 9, 2009

It is customary for me to write an article for the newsletter. In October 2009, when the original table of contents and design for this issue were created, Lynda Sedefian set aside spacing for this article which would consist of 650 words. For weeks I struggled to write this letter. At first I attributed the request of brevity to be the challenge. I have written so many versions of this letter and then have had to go back and change it.

The actual basis of this challenge would not be evident to me until last week. This letter was not mine to write. Michael died on December 9, 2009. This was just two days after we celebrated his 23rd birthday. This letter was intended to honor the life of my beloved son.

Michael has gone through so many challenges, but he always met each of them with bravery. He has beaten the odds so many times and always managed to make every moment count. In Michael's far too brief span of days on this Earth he made a difference. He managed to exceed any expectations his father and I could ever have imagined.

Unlike his brother Evan, Michael lived to be an adult. He experienced the best and worst life had to offer. Yet even when he encountered challenges he remained positive. Just weeks before his death Michael and I talked about this. He said "Mom, it isn't easy being me. I have to make a conscious effort to stay positive. But, I only have one life to live and don't intend to waste any of it feeling sorry for myself." Michael never indulged in self-pity. He beat the odds so many times. We have placed the shoes he was wearing when he was given last rites at the age of 13 months next to the shoes he was wearing at the age of 23. This serves as a poignant reminder of Michael's determination.

In the days since his death so many people have said, "I wish I had spent more time with Michael," or "I wish I knew him better but the time I did have with him made a difference." Michael somehow knew he had a great deal to do and never counted on tomorrow to accomplish it. He lived in the moment and free from the burden of regret that many who are decades beyond his years of experience have when reflecting on their life's accomplishments. We too wish we had more time with Michael. But even if Michael were to leave this earth with silver hair it would have been too soon if his death preceded those who loved him.

Grief is indeed the price we pay when we allow ourselves to love. The depth of our grief is a reflection of the depth of love we had for Michael. I never allowed myself to ponder a world without Michael. It would have been a waste of precious time.

Everlasting life starts here and now, right here on this Earth. Every positive difference we make in the lives of others is renewed for generations to come. The evidence of this truth unfolds every day in many ways.

Michael's sister, Alanna, sang the Hollies song *He Ain't Heavy, He's my Brother* during his memorial service. She broke down in tears as she sang this song. Everyone in attendance, including myself, wanted to rush to her but we didn't because we all knew it was something she had to do. Following the service Alanna said, "I didn't quit because Michael would never have let me live it down. He was never a quitter and I wasn't going to quit on him." This truth about my son gave me the strength to write this letter. I would not be able to write this letter in 650 words or less. But in the end that was not the challenge.

(Cont'd on page 3)

(Cont'd from page 2)

This would be a different letter from any other I had ever written. While it was difficult to write, it was intended to be my tribute to my son, my hero. He lived his life to the fullest. He was determined to live his life his own way driven by his own convictions. Michael defied the odds. In the days since his death I find myself overcome by awe and inspiration of his character just as I had been so many other times throughout his life. He lived his life fully and that is what has brought comfort to us in these most difficult days.

I close this article by sharing an essay Michael wrote when he was 15 years of age. Michael managed to do something I never could. In a few brief paragraphs he captured the mantra that would define his life and once again leave us all in awe and inspired.



FEAR IS NOT MY OPTION

BY MICHAEL J. BOWEN, JR.

December 7, 1986—December 9, 2009

I am a mortal human being. I have no special powers to live forever. From the moment we take our first breath cells begin to die. I have a rare disorder called Barth syndrome. I refuse to let the term life-threatening define me. Life itself is life-threatening.

The greatest of all fears is the fear of death. The irony is death happens to every one of us. Life will always come to an end. People often fret over how they will die or what malady will happen to them. Sometimes things happen to us that are out of our control. We can fear these things or we can be courageous about them.

Some people are afraid of snakes even though they have never encountered a snake. Some are afraid of bats or other silly things like that. When I was old enough to realize death: The worst thing that could happen to anyone is going to happen to everyone I chose not to waste my life by living in fear but moreover to be fearless. Fear paralyzes where courage sets us free.

I will not waste my time living in fear. I will live my life to the fullest. I will not consider what will come of me because I am not any different than any other mortal human being. I will come and I will go, that much has been defined for me. I have been fortunate enough to draw a first breath that defined the start of my life and I know my last breath will define the end my life. I choose to make the breaths between my first and last the living years. It is not my choice about when the first and last breath occur but it is up to me to define how I live my life with every breath between. Therefore I refuse to allow fear to define how I live my life.



*Michael Bowen visits with Dr. Peter Barth in Amsterdam in 1996. During that visit, it was Dr. Barth who told Shelley to go back and find other diagnosed families because he knew they were out there. That is exactly what she did!
(Photo courtesy of the Bowen Family.)*

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Hope With a Profound Sense of Urgency

By Linda Stundis, Executive Director, Barth Syndrome Foundation

One year ago, I wrote my first Barth Syndrome Foundation journal article entitled, *An Extraordinary Community with a Profound Sense of Urgency*. As I write today, so soon after losing Philip, Michael and Jamal, the sense of urgency is palpable.

The day after Michael died, the BSF Scientific and Medical Advisory Board (SMAB) met in New York City for a long-planned annual meeting. The timing was powerful. The SMAB members felt the profound sense of urgency, and all agreed that we must push back the boundaries of science and medicine with unrelenting vigor and purpose in our search for a cure for Barth syndrome (BTHS).

Flying down to Florida after the SMAB meeting, I was rethinking my newsletter article and decided to incorporate two quotes that I often think of in relation to BSF. The first is by Margaret Mead, who said, *Never doubt that a small group of committed citizens can change the world, indeed, it is the only thing that ever has...* Is there anyone who doesn't think BSF could be the poster child for this quote?

The second quote is by the founder of Citizens Schools who said, *Social change is a team sport*. Well, to paraphrase, changing the world of BTHS is a team sport. We can only be successful if our fight against this disease is a team effort: families sharing the burden of BTHS with one another, supporting one another at all hours of the day and night, answering the call when our dedicated researchers need participants for a clinical study, and participating (please, if you are not doing so already!) in the Medical Database and BioRepository; physicians and scientists working tirelessly to understand BTHS; our donors, giving time and again, year after year, making all we do possible; our volunteers, ready and willing to help where and when needed; and of course the staff, who must go above and beyond on a daily basis.

As we approach the 10th anniversary of BSF, which we will celebrate at the International Conference in July 2010, we are reminded of the tremendous accomplishments of the past nine years. BSF is a tribute to all the families, physicians, scientists, donors, and volunteers to date who have helped advance our mission, *Saving lives through education, advances in treatment, and finding a cure for Barth syndrome*.

But our work now is more demanding than ever. One of my favorite poets, Jorge Luis Borges wrote, *Hope and fear are twin faces of the same coin*. I did not have the privilege of knowing Philip or Jamal, but I know that Michael was a truly remarkable young man—knowing fear, but heroically living his life beyond the constraints of fear. Most of us know fear all too well and struggle mightily with the tension between hope and fear—especially at times like these. But, despite the fear, and embracing the hope, we all must work harder still and with heightened urgency to ensure that the next decade brings even greater advances in understanding, treating, and finding a cure for BTHS.



Keeping Hope Alive ... Thoughts from Barth Families

...If we were to give up on hope, we'd be giving up on Shelley right when she needs us the most. I know that she would comfort everyone who has been where she is today and that she would exhort the rest of us to grab our kids and hold them close, grab life and love, laughter and tears and live every minute of it. I include our special doctors, scientists, extended families, fundraisers, donors and volunteers in our thoughts because I know that this loss has touched you too. After all, we would never have such dedication from you all without love. And without you, we would have no hope at all. ~ Michaela Damin

...Our Barth family has suffered so many losses over the past eighteen months. We have to find answers and we have to stop this! We are all going to have to pitch in to do this. We need to help each other and our boys. I love all of you and I hope I am able to see all of you at the 2010 Conference in Orlando so we can find more answers together. There is strength in numbers, we may not be the biggest group, but we are mighty and a force to be reckoned with. ~ Michelle Telles

...A few years ago, my husband, Mike, and I were at a medical conference manning the BSF booth. Dr. Barry Byrne came by our booth with several other doctors with him. He introduced us all and said to his colleagues, "This group is the SWAT team of parents." We all laughed...but he's right. We have been the SWAT team of parents—led by our Shelley in every way.... Let's not drop back now. Let's step up even more. ~ Sue Wilkins

...While I am so very sad, I could not agree with you all more that we must move forward and we must remain hopeful because the SWAT team still has quite a bit of work to do for all of our sons and for those yet to even be born. ~ Julie Floyd

...We need to come together now more than ever! Thank goodness the BSF conference is coming up! However, let's not wait till then. Let's continue our focus with renewed determination and vigor letting the memories of those who have passed and the lives of these courageous boys propel us forward... ~ Bryan Drake

5th International Scientific, Medical and Family Conference

Join Us in Celebrating BSF's 10th Anniversary!

(Cont'd from page 1)

Since our Conferences are so important in bringing as many families as possible together for a week, in collecting a volume of clinical data that is otherwise impossible at one time, and in the ongoing education and sharing of research data, we wanted to ensure the greatest possible number of attendees. For these reasons, the decision was made to move the location of our 2010 Conference to the Renaissance at SeaWorld located in Orlando, FL.

The BSF 5th International Conference is a must-attend event for seasoned Conference attendees and new families, physicians, and researchers alike. Families can consult the world's leading experts on Barth syndrome (BTHS) and meet other families with BTHS, and researchers can learn about the latest advances in research from around the world.

Currently we have a Planning Committee for the Family Sessions comprised of staff and 29 volunteers to date, and includes subcommittees for the clinic, logistics, the family track, social events, young adults, and communications. If you are not yet involved and would like to be, please contact Lynda Sedefian (Lsedefian@barthsyndrome.org).

The complete Conference schedule follows this article, but highlights include:

Barth Clinics: Once again BSF will be offering two days of clinics. Families will have the unique opportunity to consult with the experts in one-on-one meetings to address specific personal concerns. Nowhere else can you find such a coming together of doctors who have specialized in the various aspects of BTHS. At the same time, critical data will be gathered for our fight against this disorder.

Family Sessions: The family program will include presentations of the most up-to-date information on BTHS. There will be updates on research, cardiac and arrhythmia concerns, hematology and clinical manifestations of the syndrome and how to treat them. Families will have the opportunity to ask questions and participate in smaller age-specific breakout discussions to discuss everything from birth to adolescence, college and growing up with BTHS. Here you will gain a better understanding of living with the complex symptoms of BTHS and learn coping mechanisms and strategies from those who know best—the families themselves. Relationships made at the conferences form a safety net and endure for life.

Affected Individual and Sibling Programs: There will be programs specifically designed for and by the young attendees. New participants will meet others and form lasting relationships, and experienced attendees will have ample time to strengthen friendships and form new bonds.

The Renaissance at SeaWorld is in a prime Orlando location across from SeaWorld and adjacent to Discovery Cove. Other Orlando attractions are minutes away. The Resort has several on-site restaurants, and a floor plan which provides easy access to guest rooms, meeting rooms, restaurants, and outdoor amenities. More information about the Renaissance is available on the BSF website www.barthsyndrome.org.

Register now at www.barthsyndrome.org and help us celebrate the 10th Anniversary of BSF and all the work that has been done to date to serve and educate our families and the advances in research that are moving us closer to treatment protocols and a cure!

Please see page 6 for an overview of the Conference, as well as important information on registering with BSF and the Renaissance at SeaWorld.



**Barth Syndrome
2010 International Scientific, Medical & Family Conference**

**Renaissance at SeaWorld
Orlando, FL
July 26–July 31, 2010**

MAKE YOUR RESERVATIONS NOW!

A dedicated booking website has been created for this event so you will be able to make your hotel reservations on-line, as well as take advantage of any room upgrades, amenities or other services offered by the hotel.

To reserve your hotel room at the Renaissance at SeaWorld via the internet, please click 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 (US \$115/per night).

In addition to making your hotel reservation, you will need to register for this Conference with the Barth Syndrome Foundation on-line at www.barthsyndrome.org. For assistance or further information, please contact bsfinfo@barthsyndrome.org.

	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



Scientific & Medical Session of BSF's 2010 International Conference

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

The 5th International Scientific, Medical & Family Conference on Barth syndrome being held in July 2010 will continue its rich tradition of highlighting the progress on understanding this unique mitochondrial disease. The chairs for the Scientific and Medical session will be four members of the BSF's International Scientific and Medical Advisory Board: Dr. Richard I. Kelley, Dr. Barry J. Byrne, Dr. Miriam L. Greenberg, and Dr. Michael Schlame. Twenty-seven speakers will be revealing the results of their scientific and clinical research, much of which has been facilitated over the years by grants from the BSF.

These speakers will provide for an intense two-day meeting where almost all the researchers on Barth syndrome will be assembled to hear the latest developments taking place. Importantly, this gathering will also serve to start and to renew collaborations between researchers and to revitalize the efforts of finding a specific treatment for Barth syndrome.

There will also be the usual poster session where other researchers can communicate their work and receive feedback from the attendees. As with previous Conference Poster Sessions, some travel stipends will be offered particularly for younger investigators. (See below for Call for Poster Abstracts.)

Scientific & Medical Session Keynote Speaker Announcement

On behalf of the 2010 Science and Medicine Conference Organizing Committee, we are pleased to announce that Douglas C. Wallace, PhD will be our keynote speaker. Dr. Wallace, one of the world's leading authorities on mitochondrial DNA, is Donald Bren Professor of Molecular Medicine and Director of the Center for Molecular and Mitochondrial Medicine & Genetics at the University of California at Irvine, and is a member of the Scientific & Medical Advisory Board of the United Mitochondrial Disease Foundation. Dr. Wallace was recently elected a member of the Institute of Medicine (IOM), the health branch of the National Academy of Sciences. He is also a member of the National Academy of Sciences and the American Association for the Advancement of Science.

Dr. Wallace is one of the earliest pioneers in defining the importance of the mitochondria in human disease. He describes himself as a "mitochondriac," and we are very glad he will be able to join us in July 2010.

2010 BSF International Scientific & Medical Conference Call for Poster Abstracts

The Barth Syndrome Foundation 2010 Scientific and Medical Conference Organizing Committee (COC) invites the submission of abstracts for poster presentations related to the scientific and/or clinical aspects of Barth syndrome. The deadline for abstract submission is April 15, 2010. All submitted abstracts will be peer-reviewed by the COC. Once accepted, the submitting author will be expected to present his/her corresponding poster at a specific time during the Conference.

Details of the submission process are available at www.barthsyndrome.org.

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

Travel stipends (up to \$800) will be available based on need as well as quality of the poster. Completion of an additional form (available on our website at www.barthsyndrome.org) is required to apply for this funding, and we particularly encourage young investigators (including doctoral and post-doctoral attendees) to apply for this feature of the Conference.

Highlights of BTHS Clinical Data Meeting

(Cont'd from page 1)

Another important outcome of this meeting was the need to establish the types of data to be collected at the 2010 Conference Clinic. Please note that in the coming months, several researchers will be asking for volunteers to follow up on the observations made in 2008 and other clinics (see pgs. 12-13). We hope that as many families as possible will participate. The information gathered at the Conference clinics provides us with one of the best ways to generate new and specific therapeutic ideas.



BSF Encourages Collaboration Among US Diagnostic Laboratories—Highlights of Genetic Diagnosis of BTHS Meeting

By Linda Stundis, Executive Director, Barth Syndrome Foundation, on behalf of Shelley Bowen

It has been one of our long-standing goals to build relationships among BSF and the diagnostic laboratories in the US. The three primary genetic labs in the US working on Barth syndrome (BTHS) are Baylor, Harvard, and A.I. duPont. As you all know, we have had and continue to have a close working relationship with Dr. Iris Gonzalez and Susan Kirwin, Senior Research Associate at the A.I. duPont lab. In addition, Dr. Gonzalez curates our DNA database while Ms. Kirwin is a BSF research grant recipient.

BSF and the genetic labs have faced challenges in fully serving the needs of BTHS patients and their families. Diagnosis is often difficult, and some clinical criteria, such as 3-methylglutaconic aciduria, can give misleadingly negative results depending upon the testing methodology used. As a result, Shelley Bowen has long envisioned collaboration among the major genetic labs testing for BTHS, the Barth Syndrome Medical Database & BioRepository (BRR), and BSF families.

Yuxin Fan, MD, PhD, FACMG is the Director of the John Welsh Cardiovascular Laboratory at Baylor and Birgit Funke, PhD, FACMG is Instructor in Pathology with BTHS expertise at the Harvard Laboratory for Molecular Medicine.

Last spring, Shelley met with Dr. Fan in Houston. As a result of their meeting, Dr. Fan indicated that he was looking forward to collaborating with the duPont and Harvard labs. Shelley then contacted Dr. Funke at Harvard who was also excited about collaborating, and of course Dr. Gonzalez was on board. Because Boston appeared to be the best location for the meeting, and because Shelley could not leave Florida with her son, Michael in the hospital, she asked me to orchestrate and lead the meeting which was held on October 13, 2009.

In attendance were lab representatives Drs. Fan, Funke, and Gonzalez; Dr. Richard Kelley, BSF SMAB Chairman; Dr. Carolyn Spencer, Co-Principal Investigator, Barth Syndrome Medical Database & BioRepository; Dr. Amy Roberts, Harvard Medical School Clinical Geneticist and Director, Cardiovascular Genetics Research Program, Children's

Hospital, Boston; Linda Stundis, BSF Executive Director, and Dr. Matt Toth, BSF Science Director. Areas of discussion included:

- Sharing the results of DNA sequencing with Dr. Gonzalez for the DNA database;
- Following up with doctors treating those confirmed to have BTHS to encourage the families to enroll the child in the BRR;
- Collaborating with other laboratories to determine an approach to follow up with those who have been tested but don't have mutations in the TAZ DNA;
- Collaborating with other diagnostic labs to better identify modifier genes and modifying factors that may provide a better understanding of the genotype/phenotype of BTHS; and
- Creating a standard protocol for forms to accompany specimens screened for TAZ mutations.

In addition, it was agreed that when specific criteria are developed for the BRR to identify "Barth-like" patients, the labs would encourage the doctors treating "Barth-like" patients to recommend that families enroll the "Barth-like" patients in the BRR.

Exciting next steps include drafting recommendations for lab reports referencing "variations of unknown significance," and referencing the BSF website; updating the BSF website to include contact information for consulting BSF physicians, and "diagnostic tools" such as follow-up tests and referral papers; and inviting Drs. Fan and Funke to BSF's 2010 Conference.

As a result of Shelley's vision, the relationships built and the collaborations begun at this meeting are an enormous step forward in our efforts to better serve BTHS families and to better understand BTHS.



Special Needs Planning

U.S. Focused Q & A

By Beth Polner Abrahams, Esq., Garden City, New York



Beth Polner Abrahams, Esq., is admitted to practice law in New York State and concentrates in special needs and estate planning, elder law, and guardianship. Since 1982, Ms. Polner Abrahams' broad legal background has included Federal and state litigation on behalf of the disabled and poor on Long Island, New York, advocating for equal housing opportunity with a nonprofit fair housing agency, Long Island Housing Services, and Federal and New York State banking law with the FDIC. In 2009, Ms. Polner Abrahams was presented with an award from the New York State Bar Association's Elder Law Section recognizing her pro bono litigation advancing the rights of the elderly and persons with disabilities.

Special needs planning for a family with a disabled family member may mean different things depending upon your state of residence. In general, it may include preparation of wills or trusts to protect a disabled child's inheritance with a special needs trust and evaluating future management of an adult disabled child's person and property. If your disabled family member lacks sufficient legal capacity to manage health care decisions and/or financial resources, you may need to be appointed as legal guardian. What does legal guardianship mean? In different states, it means different things but see if you understand the basics:

CAN YOU ANSWER THESE QUESTIONS CORRECTLY?

1. When my disabled child turns age 18, I will be able to:

- A. Continue to make all health care decisions for him or her
- B. Continue to make some of the health care decisions for him or her
- C. Make none of the health care decisions

Answer: (C) Make none of the health care decisions

The law presumes every adult age 18 and older is competent to make his or her health care decisions. While your local physician may continue to permit you to make health care decisions for your adult child, it is not the law. Privacy laws, such as HIPAA, often bar parents from communicating with health care professionals, particularly in hospitals. If surgery or emergency care is needed, you may not be permitted to make decisions nor have input if you have not been appointed as the legal guardian for your adult child.

Before going to court to be appointed as legal guardian, speak with a qualified attorney and appropriate medical or psychology practitioners to determine if your child's impairment prevents him or her from signing an advance directive for health care decisions, called a Health Care Proxy or Health Care Power of Attorney, and financial power of attorney, instead of a legal guardianship proceeding. There may be different types of legal guardianship proceedings in your state. Some states, including New York, have more than one type of guardian appointment. One proceeding is based upon a specific diagnosis of either mental retardation or developmental disability. Another proceeding declares an individual incapacitated rather than incompetent, without specific diagnosis, based upon whether the disabled individual is able to arrange for their basic needs, such as food, clothing and shelter, make health care decisions, and manage finances, and that harm will result without a guardian appointed.

2. I must apply for SSI when my disabled child turns age 18 or the Social Security Administration will make us wait until my child is over age 21 years and/or out of school:

- A. True, because all benefits must be applied for at the age of 18
- B. False, the failure to apply between age 18 and 21 does not affect the application process or future benefits from SSI
- C. False, the failure to apply between age 18 and 21 does not affect the application process but might affect future benefits from SSI or Social Security

(Cont'd on page 10)

Special Needs Planning

(Cont'd from page 9)

Answer: (C) False. The failure to apply between age 18 and 21 does not affect the application process but might affect future benefits from SSI or Social Security.

Generally, most families must wait until their disabled child turns age 18 to apply for SSI (a cash benefit program) through the Social Security Administration. This is because of parental 'deeming'—the parents' income and resources are presumed available for the child. If you are low income, disabled or retired and have assets less than the Social Security poverty standard, your disabled child may be eligible for SSI and Medicaid before age 18.

If you do not apply for SSI at age 18 for your child, you may still apply at any time. However, SSI cash benefits may not be retroactive to age 18. You may also need to establish that disability began before age 22, regardless of when you apply, to preserve certain Social Security benefits derived from the parents' work history. It is best to apply for SSI between ages 18 and 21.

3. My family does not have to provide a protected inheritance through a special needs trust for our disabled child because the federal and state governments will always be there for their needs:

- A. True, the government has committed to providing the same level of benefits for our neediest individuals
- B. False, state and federal governments expect to cut funding for housing and other programs for all populations in need of such services
- C. Partially false, as programs experience cuts in government funding, you may see the need for private and voluntary assistance, and special needs trusts are one way to secure the future of your disabled child

Answer: (B) and (C) False and partially false. As programs experience cuts in government funding, these programs may need to ask for private and voluntary assistance, and special needs trusts are one way to secure the future of your disabled child.

Gone are the days when the government will fund each and every program for persons with disabilities. Cuts are expected in housing services and supports for persons with disabilities, and services may also see reversals in growth. Protecting your loved one's inheritance with a Special Needs Trust (SNT) provides an important source of funds for your adult child throughout their life to make up for things the government no longer supports. Special Needs Trusts may be drafted into your wills, trusts or other documents. Consult with a qualified attorney in your state.

For more information, go to www.bpasntlaw.com.



BSF SouthEast Family Outreach

Nine families were represented at this year's SouthEast Family Outreach. Also in attendance were Linda Stundis, BSF Executive Director, Dr. Matt Toth, BSF Science Director, Dr. Paul Fernhoff, Associate Professor of Human Genetics and Pediatrics, Emory University, and Karlene Coleman, RN, MN, CGC, Senior Associate, Genetic Counselor, Department of Human Genetics, Emory University School of Medicine. Dr. Fernhoff presented on the unpredictable nature in the symptoms of genetic metabolic diseases such as BTHS; Ms. Coleman presented on genetic variants and disease causing mutations; and Dr. Toth presented an update on Barth syndrome research.



Dr. Fernhoff presents on the unpredictable nature in symptoms of genetic metabolic diseases such as BTHS at BSF's SouthEast Family Outreach.



Karlene Coleman (R) presents on genetic variants and disease causing mutations. Julie Floyd (L) and families in attendance actively participated.

Science & Research Corner

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

As can be seen in bar graph of Figure 1, the number of relevant scholarly articles concerning Barth syndrome (BTHS) increased dramatically in 2009, with the final tally still to be reckoned. It is also evident that the number of publications that acknowledge BSF support (upper portion of bars) has increased, which is probably the result of the increased number of research grants awarded by the BSF, and the increased participation in the International Scientific, Medical & Family Conferences over the past several years. What is truly exciting is that the author lists of several of the publications appear to have been the result of close collaboration between the individual researchers, who are often geographically distant from each other.

Publications

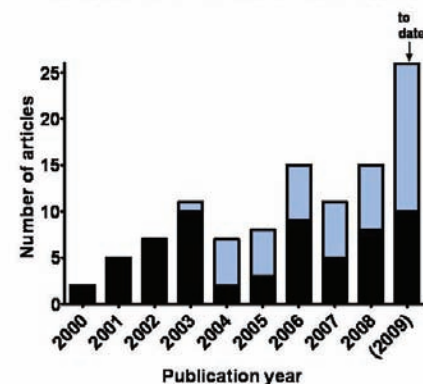
Publications are one aspect that we can use to show scientific progress. Like unemployment rates in the present economy, this parameter is a “lagging indicator,” meaning that this type of measurement takes a period of time to be seen. Another measure of progress is the number of grants awarded by outside agencies and the number of people interested in applying to our BSF Research Grant Program. Previously, I reported on the extraordinary number of NIH grants that have been awarded to BTHS researchers. These indicators point to a greater interest in BTHS research.

Tafazzin Knockdown Mouse

As previously reported, the tafazzin knockdown mouse has been developed through a contract with TaconicArtemis of Cologne, Germany. There are currently four laboratories studying the mice. We hope that the data gathered will allow these and other laboratories to pursue the mysteries of BTHS on a deeper level than can be done now.

(Cont'd on page 12)

Relevant PubMed Articles



(Search terms: Barth syndrome, tafazzin, cardiolipin)

Figure 1: Publications involving BTHS by year of publication. Note that before 2000 there were only 11 publications in total. Upper portion of the bars refer to BSF acknowledgement.

Dr. DiMauro Retires from SMAB

By Kate McCurdy, Board Member, Barth Syndrome Foundation



Salvatore DiMauro, MD, known as Billi, retired from BSF's Scientific and Medical Advisory Board (SMAB) at the end of November when his latest term was finished. He had been a member of the SMAB since it was first created in the Fall of 2001. We certainly are sorry to see him go, but we are very grateful for all the advice he has given our organization and the expertise he has so generously shared with us all.

To summarize some of his credentials for those who may not know him well, Dr. DiMauro is the Lucy G. Moses Professor of Neurology at Columbia University Medical Center in New York City. He is known throughout the world as an expert on mitochondria and is frequently sought after as a keynote speaker for international meetings. In addition, he runs the Laboratory of Molecular Neurogenetics to help diagnose mitochondrial disorders and metabolic myopathies. His lab has been involved in the analysis of a number of muscle biopsies from BTHS patients over the years, so many of us are personally indebted to him and his expertise. Furthermore, Dr. DiMauro has been a wonderful counselor to BSF as we have developed and evolved both our grant program and the review process with which we evaluate the applications that we receive. He has offered a long-term perspective that has been invaluable and quiet wisdom that has been essential.

And perhaps most importantly, Dr. DiMauro encouraged Dr. Michael Schlame to become interested in working on BTHS. In the very beginning when Dr. Schlame needed some specimens in order to conduct his early work on cardiolipin, Dr. DiMauro gave him some and suggested that he get in contact with BSF for whatever else he needed. That original work led to a very dedicated, productive and important research effort that continues today.

We certainly will miss Dr. DiMauro, but we all wish him the very best as he begins to wind down his incredibly busy and successful career in a scientific and medical field that has made a huge difference to many in the world. His association with BSF has enhanced us all. Thank you very much, Billi; we are extremely grateful for what you have given us.

Science & Research Corner

(Cont'd from page 11)

While we wait on the developments from the mouse model of Barth syndrome, there are two clinical experimental protocols that are available for the BSF community to support with their participation. Through his 2008 BSF research grant, Dr. Todd Cade is recruiting BTHS individuals to follow-up on the observations made at the 2008 Conference Clinic (*see below*). At the Clinic, several interesting discoveries were observed. The follow-up experiments require the travel of the BTHS individual and parent to St. Louis, Missouri and an overnight stay. The subjects also will get compensated \$350 for their time and effort. The other clinical program is the intellectual testing of pre-school BTHS individuals to determine if there are related learning deficiencies. Dr. Michèle Mazzocco received a 2006 BSF research grant to carry out this testing and performed some of this work at the 2008 Conference Clinic. Dr. Mazzocco is in need of additional young participants (*see page 13*).

Project Title: Characterization of Nutrient Metabolism in Barth Syndrome

Research Team:

W. Todd Cade, PT, PhD (Principal Investigator, Washington University)
Dominic Reeds, MD (Co-Investigator, Washington University)
Linda Peterson, MD (Co-Investigator, Washington University)
Melissa Maisenbacher, MS, CGC (Co-Investigator, University of Florida)
Barry Byrne, MD, PhD (Consultant, University of Florida)
Carolyn Spencer, MD (Consultant, Boston Children's Hospital)
Sara Hayes, RD (Research Coordinator, Washington University)

Contacts:

Sara Hayes	hayess@wustl.edu	314-517-3977
Melissa Maisenbacher	maisemk@peds.ufl.edu	352-273-8218
Todd Cade	tcade@wustl.edu	314-286-1432

Purpose of study:

The purpose of this pilot study is to collect preliminary data on the role of nutrient (fat, sugar, protein) metabolism in heart failure in boys with Barth syndrome (BTHS). In other words, do boys with Barth syndrome metabolize nutrients differently than those without BTHS and if so, does this contribute to heart failure seen in this condition?

How many subjects are you looking for?

For this pilot study, we are looking for five boys with BTHS, 15 to 30 years old, ideally without ICD's. We are also looking for five boys 15 to 30 years old without BTHS. These can be siblings of the boys with BTHS.

What is involved?

The two-day study involved coming to Washington University located in St. Louis, Missouri and undergoing two nutrient metabolism tests (lasting 3 and 5 hrs.), a body composition analysis (30 min.), an echocardiogram (1 hr.), a magnetic resonance imaging (MRI) scan (1 hr.).

How do I get to St. Louis and who pays for it?

We will pay for the subject's and one parent's round trip flights to St. Louis, transportation to and from the airport to Washington University and for your hotel room during your stay. The subjects also will get compensated \$350 for their time and effort.

How do I get more information?

For more information and a consent form that fully describes the study details, including the risks, please contact Sara Hayes.

This research is funded by the Barth Syndrome Foundation.

(Cont'd on page 13)



Derek, age 16, while participating in Dr. Cade's two-day nutrient metabolism study at the Washington University, St. Louis, MO.
Photo courtesy of BSF ~ 2009.

(Cont'd from page 12)

Project Title: Early Indices of Learning Difficulties in Young Boys with Barth Syndrome



*Michèle Mazzocco, PhD, Director
of Math Skills Development
Project, Kennedy Krieger Institute*

Although the physical phenotype of Barth syndrome (BTHS) is well established, much less is known about whether BTHS affects the development of cognitive skills and educational achievement. In 2007, we published a report that showed a slightly lower level of academic achievement among primary school age boys with BTHS, compared to boys of the same age and school grade without BTHS (Mazzocco, Henry, & Kelley, 2007). An unresolved question is whether any academic achievement differences that we observed are linked directly to BTHS, or are secondary to other characteristics of the syndrome such as fatigue or school absences associated with frequent illness. To address this question, a study is currently underway that involves evaluating early academic related skills in boys who have not yet begun, or only recently begun, formal education.

What is the purpose of this research project?

This project is designed to help understand the development of cognitive and academic skills in young children. One component of the project involves assessing the level of these skills in preschool and primary school children with BTHS. We are currently recruiting children who are 3 to 7 years of age, who have not yet completed kindergarten, and who have BTHS.

What does participation entail?

Participation will involve several hours of cognitive testing which will occur over one or two days. The testing includes measures of pre-reading, mathematics, spatial reasoning, and other problem solving skills. The testing will occur at the Kennedy Krieger Institute, or elsewhere, depending on your geographic region of residence. There are no direct medical benefits to joining this study, and you will not be paid for your child to join this study. There is, of course, no charge for any of this testing.

Who do I contact if I'm interested?

If you desire more information about this project, or if you wish to enroll your child, please contact: Dr. Michèle Mazzocco, Principal Investigator, (443) 923-4125; mazzocco@kennedykrieger.org, JHU Research Protocol 95-05-26-02. This research is funded by the Barth Syndrome Foundation.

Articles of Interest:

Mazzocco MM, Henry AE, Kelley RI. **Barth syndrome is associated with a cognitive phenotype.** J Dev Behav Pediatr. 2007 Feb;28(1):22-30.

Mazzocco MM, Kelley RI. **Preliminary evidence for a cognitive phenotype in Barth syndrome.** Am J Med Genet 2001 Sept 1; 102(4):372-378.

Photos courtesy of Amanda Clark ~ 2008



BSF Involved in Effort to Create a Global Rare Disease Registry

By Kate McCurdy, Board Member, Barth Syndrome Foundation

The Office of Rare Disease Research (ORDR) at the National Institutes of Health (NIH) is organizing a workshop in January 2010 at which relevant thought leaders will be brought together to discuss the idea of establishing an international Rare Disease Patient Registry. The objective of the meeting is “to discuss the development of an infrastructure for an internet-based platform with common data elements utilizing a federated rare disease registry able to incorporate:

- 1) existing rare disease registries and any other useful patient registries;
- 2) patient organizations with no registry looking to establish one; and
- 3) patients with no affiliation with a support group looking to belong to a registry.”

As the result of ORDR’s knowledge of the Barth Syndrome Medical Database and BioRepository, the NIH invited me, as a representative of BSF, to be on the planning committee for this workshop. This is wonderful recognition of our collaborative accomplishments to date. We know that we will all benefit from being included in these discussions and in this exciting, important effort, and we will certainly report back after the meeting.

NIH Research Initiatives Relevant to Barth Syndrome

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

Application of Metabolomics for Translational and Biological Research (R01)

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

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

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

Program Announcement (PA) Number: PA-07-097 (and the R21 version for pilot/exploratory projects: PA-07-099 and the R03 version for small research grants: PA-07-098)
Letters of Intent Receipt Date(s): N/A
Expiration Date: January 3, 2010 (now January 8, 2010 per [NOT-OD-07-093](http://grants.nih.gov/grants/guide/pa-files/PA-07-097.html))<http://grants.nih.gov/grants/guide/pa-files/PA-07-097.html>

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

Diet Composition and Energy Balance (R01)

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

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

NIAMS Small Grant Program For New Investigators (R03)

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

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

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



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 47 articles published with the support of BSF and/or BSF affiliate funding (denoted below with an asterisk). 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. 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 15. [Epub ahead of print]
2. Gebert N, Joshi AS, Kutik S, Becker T, McKenzie M, Li Guan X, Mooga VP, Stroud DA, Kulkarni G, Wenk MR, Rehling P, Meisinger C, Ryan MT, Wiedemann N, Greenberg ML, Pfanner N. **Mitochondrial Cardiolipin Involved in Outer-Membrane Protein Biogenesis: Implications for Barth Syndrome.** *Curr Biol.* 2009 Dec 2. [Epub ahead of print]*
3. Hauff KD, Choi SY, Frohman MA, Hatch GM. **Cardiolipin synthesis is required to support human cholesterol biosynthesis from palmitate upon serum removal in HeLa cells.** *Can J Physiol Pharmacol.* 2009 Oct;87(10):813-20.*
4. Mancuso DJ, Kotzbauer PT, Wozniak DF, Sims HF, Jenkins CM, Guan S, Han X, Yang K, Sun G, Malik I, Conyers S, Green KG, Schmidt RE, Gross RW. **Genetic ablation of calcium-independent phospholipase A2 γ leads to alterations in hippocampal cardiolipin content and molecular species distribution, mitochondrial degeneration, autophagy and cognitive dysfunction.** *J Biol Chem.* 2009 Oct 19. [Epub ahead of print]
5. [No authors listed] **A new look at Cardiolipin.** *Biochim Biophys Acta.* 2009 Oct;1788(10):1997-2002.
6. Melloney K, Johns, Meng-Xin Yin, Stuart J, Conway, Diane E. J, E. Robinson, Leon S.-M. Wong, Rebecca Bamert, Richard E. H. Wettenhall and Andrew B. Holmes. **Synthesis and biological evaluation of a novel cardiolipin affinity matrix.** *Org Biomol Chem.* 2009 Sep 21;7(18):3691-7. Epub 2009 Jul 14.
7. Zachman DK, Chicco AJ, McCune SA, Murphy RC, Moore RL, Sparagna GC. **The role of calcium-independent phospholipase A2 in cardiolipin remodeling in the spontaneously hypertensive heart failure rat heart.** *J Lipid Res.* 2009 Sep 9. [Epub ahead of print] *
8. Taylor WA, Hatch GM. **Identification of the human mitochondrial linoleoyl-coenzyme a monolysocardiolipin acyltransferase (MLCLAT-1).** *J Biol Chem.* 2009 Sep 8. [Epub ahead of print]*
9. Xu Y, Zhang S, Malhotra A, Edelman-Novemsky I, Ma J, Kruppa A, Cernicica C, Blais S, Neubert TA, Ren M, Schlame M. **Characterization of tafazzin splice variants from humans and fruit flies.** *J Biol Chem.* 2009 Aug 21. [Epub ahead of print] *
10. Sorice M, Manganelli V, Matarrese P, Tinari A, Misasi R, Malorni W, Garofalo T. **Cardiolipin-enriched raft-like microdomains are essential activating platforms for apoptotic signals on mitochondria.** *FEBS Lett.* 2009 Aug 6;583(15):2447-50. Epub 2009.
11. Rijken PJ, Houtkooper RH, Akbari H, Brouwers JF, Koorengel MC, de Kruijff B, Frentzen M, Vaz FM, de Kroon AI. **Cardiolipin molecular species with shorter acyl chains accumulate in *S. cerevisiae* mutants lacking the acyl-Coenzyme A-binding protein Acb1p. New insights into acyl chain remodeling of cardiolipin.** *J Biol Chem.* 2009 Aug 5. [Epub ahead of print]*
12. Hastings R, Steward C, Tsai-Goodman B, Newbury-Ecob R. **Dysmorphology of Barth syndrome.** *Clin Dysmorphol.* 2009 Jul 30. [Epub ahead of print]*
13. Houtkooper RH, Turkenburg M, Poll-The BT, Karall D, Pérez-Cerdá C, Morrone A, Malvagia S, Wanders RJ, Kulik W, Vaz FM. **The enigmatic role of tafazzin in cardiolipin metabolism.** *Biochim Biophys Acta.* 2009 Jul 18. [Epub ahead of print]*
14. Shah KB, Duda MK, O'Shea KM, Sparagna GC, Chess DJ, Khairallah RJ, Robillard-Frayne I, Xu W, Murphy RC, Des Rosiers C, Stanley WC. **The Cardioprotective Effects of Fish Oil During Pressure Overload Are Blocked by High Fat Intake. Role Of Cardiac Phospholipid Remodeling.** *Hypertension.* 2009 Jul 13. [Epub ahead of print]
15. Mitchell RW, Hatch GM. **Regulation of cardiolipin biosynthesis by fatty acid transport Protein-1 IN HEK 293 Cells.** *Biochim Biophys Acta.* 2009 Jun 10. [Epub ahead of print]
16. Pass KA, Thoene J, Watson MS. **Emergency preparedness for newborn screening and genetic services.** *Genet Med.* 2009 Jun;11(6):455-64.
17. Storch EA, Keeley M, Merlo LJ, St. Amant JB, Jacob M, Storch J, Spencer C, Byrne BB. **Psychosocial Functioning in Youth With Barth Syndrome.** *Children's Health Care, Volume 38, Issue 2 April 2009, pp. 137-156.**
18. Cortez-Dias N, Varela MG, Sargento L, Brito D, Almeida A, Cerqueira R, Lança V, Fernandes AR, Tavares P, Pereira RA, Fernandes A, Madeira H. **Left ventricular non-compaction: a new mutation predisposing to reverse remodeling?** *Rev Port Cardiol.* 2009 Feb;28(2):185-94.
19. Osman C, Haag M, Potting C, Rodenfels J, Dip PV, Wieland FT, Brügger B, Westermann B, Langer T. **The genetic interactome of prohibitins: coordinated control of cardiolipin and phosphatidylethanolamine by conserved regulators in mitochondria.** *J Cell Biol.* 2009 Feb 23;184(4):583-96. Epub 2009 Feb 16.
20. Zick M, Rabl R, Reichert AS. **Cristae formation-linking ultrastructure and function of mitochondria.** *Biochim Biophys Acta.* 2009 Jan;1793(1):5-19. Epub 2008 Jun 20. Review.
21. Ichida F. **Left ventricular noncompaction.** *Circ J.* 2009 Jan;73(1):19-26. Epub 2008 Dec 4. Review.
22. Tatu-Chitoui A, Bradisteanu S. **A rare case of biventricular non-compaction associated with ventricular septal defect and descendent aortic stenosis in a young man.** *Eur J Echocardiogr.* 2008 Mar;9(2):306-8.

Patents and Patent Applications

1. Peter Wipf, Jingbo Xiao, Mitchell P. Fink, Valerian E. Kagan, Yulia Y Tyurina. **Selective targeting agents for mitochondria.** US Patent Issued: May 5, 2009. (Patent Abstract)
2. Genevieve C. Sparagna, Adam J. Chicco, Russell L. Moore, Sylvia A. McCune. **Use Of Linoleic Compounds Against Heart Failure.** Publication Date: Dec. 25, 2008. (Patent Application)

Barth Syndrome Foundation Gives Thanks to Our Loyal Supporters

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

For almost a decade, the Barth Syndrome Foundation (BSF) has looked to our friends and families to make the donations that fund our programs. “Nothing unusual in that” you say, and you would be right, but for a few small facts that put our longevity and accomplishments into perspective. There are fewer than 150 families who are directly affected by Barth syndrome (BTHS) and who have joined BSF or one of its international affiliates (many more are unknowingly affected or have yet to contact BSF). Only 150 families from around the world, most of whom live 50 or 100 miles or more from the next nearest Barth family. That means that fund raising is a very personal affair. Each family must be willing to approach its own circle of friends and colleagues to ask each one of them to contribute to BSF. It’s not easy to ask people for money. And yet, since BSF was founded in 2001, our families and friends have come through for us, contributing their hard earned funds to make our progress possible.

Our families and friends have not just “come through” but done so in a way that continues to be extremely unusual for any disorder as rare as BTHS. You, our families and friends, have made donations sufficient to support a BSF annual budget that has grown from \$6,000 in its first full year to over \$1 Million in 2008. BSF has funded over \$1.5 Million in research grants of \$40,000 or less, and have created a “bank” to record medical data on affected people and preserve samples of DNA, blood and tissue to support research. We have held four International Conferences attracting scientists, physicians and families from around the world. We attend scientific conferences to increase awareness and publish pamphlets, brochures, newsletters and maintain the most up-to-date website of information on BTHS to better inform physicians, families and the general public. We now have four professional full-time staff members who form the backbone of our programs.



(Photo #1) Michelle runs in honor of her beloved son, Michael, who passed away in April 2009. Her youngest son proudly supports her efforts!

All this, surrounded and supported by a core of fewer than 150 families around the world. We are few, but we are determined and focused. And we have the best and most supportive friends in the world! The families of BSF are firm in our pledge to ‘never give up’ in our search for a cure and our care for those who may be affected, and we are grateful for the continued support of you, our friends, who match our determination with your donations... year after year.

Here are some of the Barth families and friends who have been most actively engaged in raising money for BSF in 2009.

Running for Michael

Michelle Telles has been raising money in honor of her son, Michael, who passed away in April of this year. After Michael’s death, Michelle began to run and asked friends to contribute to BSF for each mile she ran. To date she has recruited a team of 18 sponsors and has now begun to run in honor of Michael Bowen as well and is asking people to donate for each mile she runs for both Michaels. *(Photos #1 & 2)*



(Photo #2) This photo of Michael inspired Michelle to continue her determination to raise awareness and funds for BSF.

NorthEast Family Gathering

The **Dunn Family** in cooperation with the Monahan Family, used the Northeast Family Gathering as a fundraising event. Any gathering of Barth families can become an effective time to raise both funds and awareness as the Dunns have proven for several years now. Friends and family were present at this year’s event. Entertainment was provided by the Becky Chase Band. Funds were raised, fun was had by all, and awareness of Barth syndrome was once again heightened within their community. *(Photo #3)*



Becky Chase performs at the Dunn’s NorthEast Gathering in support of BSF. (Photo #3)

(Cont'd from page 16)



(L-R) Steve Buddemeyer, along with Randy's three sons (ages 15, 20, 17) and Randy are ready to tee off to support BSF at the 4th Annual Barth/JDRF Charity Golf Tournament. (Photo #1)

CB Richard Ellis Fourth Annual Charity Golf Tournament

Fellow Floridians, **Randy and Leslie Buddemeyer** have adopted the golf tournament approach. On October 5, 2009, Randy's firm, CB Richard Ellis sponsored its Fourth Annual Golf Tournament to raise funds for BSF and the Juvenile Diabetes Research Foundation at the Emerald Greens Golf and Country Club in Tampa, Florida. CBRE and its many business partners have become enthusiastic supporters of these two causes, made more personal by the appearance of Randy's son, now 20, who was diagnosed with BTHS at the age of 14. (Photo #1)

"Driving for a Cure" 6th Annual Charity Golf Outing

For the sixth year, fellow Floridians **Jan and Steve Kugelmann** organized and ran their "Driving for a Cure" Charity Golf Outing held at the Savannahs Golf Course in Merritt Island, Florida. On October 11, 2009 over 200 golfers, volunteers and other supporters were focusing on one thing—a firm belief that they were making a difference in the lives of those affected by BTHS. Every year, Jan and Steve get calls from supporters who ask when the BSF Tournament will be, so avid are they to "Drive for a Cure"... and every year, these golfers compete for "longest drive" and "closest to the pin" honors, and the Kugelmann's 11 year old son who has BTHS draws the name of the lucky winner of the 50/50 raffle, all the while supporting BSF. (Photo #2)



Dr. Robert Sutphin from Arnold Palmer Hospital and the Kugelmann's 11 year old son prepare to greet the helicopter for the 'Ball Drop' at the 6th Annual Charity Golf Tournament raising funds for BSF. (Photo #2)

6th Annual Bowling Fundraiser

The **Higgins Family** held their 6th Annual Bowling Fundraiser on October 17, 2009 in Warwick, NY to the delight of some 50 friends and family. This event has become a must-attend for the loyal supporters in the Warwick area and draws some from miles away as well. (Photo #3)

Lakefront Marathon

Cherie Schrader is a veteran runner and an Aunt of Lattigo Cook, one of our Barth boys who passed away in 2002. In 2003, Cherie ran the Chicago Marathon in honor of Lattigo and has been racing and raising money for BSF ever since, most recently running in the Lakefront Marathon in Milwaukee, WI on October 4, 2009. A professional photographer, Cherie will be attending the 2010 Barth Conference to take photos throughout the event. (Photo #4)

(Cont'd on page 18)



Friends of the Higgins come out and bowl to support BSF. (Photo #3)



Cherie Schrader (L) continues to run in a number of marathons in honor of Lattigo (R) and in support of BSF. (Photo #4)

Barth Syndrome Foundation Gives Thanks to Our Loyal Supporters

(Cont'd from page 18)

Baking for Barth

Rosemary Baffa and friends used their creative baking skills and hosted the 'Baking for Barth' fundraiser in the fall of 2009. Donations are still in process.

Pampered Chef Fundraiser

Angela Calhoun used her cooking skills to raise money for BSF in 2009. Angie is a Pampered Chef consultant.

Team Will—Ford Ironman Arizona

Gary Rodbell, a friend of the McCurdys and BSF's "Ironman" has been an exceptionally strong friend of BSF. He and Matt Karp, Heather Segal, Ghent Lummis and Paul Epstein entered the Ironman competition in Tempe, Arizona on November 22, 2009, and through



(L-R) Team Will members Heather Segal, Paul Epstein, Ghent Lummis, and Gary Rodbell...BSF's Ironmen!

their fund raising, combined with the McCurdys, raised enough to win the Janus Charity Challenge and an additional award for BSF. "Team Will," led by Gary, has now raised just under \$1 Million for BSF over several years.



Team Captain Gary Rodbell

Annual Appeals

Kate and Steve McCurdy use a postal approach, sending a personal letter updating their friends on their 23 year old son who has BTHS, the achievements of BSF and making a personal appeal to support the foundation that means so much to them. Some of their donors have been giving regularly for nine years and more are added to the list every year.

Sue and Mike Wilkins are also using the US Post Office, sending a personal annual appeal to update their friends and business associates on their 27 year old son who has BTHS and asking their friends and business associates to support BSF. Many of their donors have also been giving regularly in support of the Paula & Woody Varner Fund which has been set up to support BSF's scientific and medical initiatives.

Marc and Tracy Sernel are also using the US Post Office, updating their friends and business associates on their four year old son who has BTHS, asking for them to support BSF.

Annual Giving

BSF Affiliates

Our BSF Affiliate in the UK, the Barth Syndrome Trust, led by Michaela Damin, have agreed to donate \$40,000 to BSF in support of research and to help transport European scientists to the next International Barth Conference in July of 2010.

Network for Good / Facebook

A number of donors are giving monthly using their credit card via Network for Good in the US or the BSF Group on Facebook. This is a simple way to contribute a smaller amount regularly that can be managed in a monthly budget.

Matching Gifts

Another important source of contributions is company matching funds. Each year, many of BSF's donors who work for companies who offer gift matching programs double their donations by asking their employer to match their donations.

Scott Oldewage is one of these and his employer, **Ed Pace**, owner of Lake City Leasing, matches Scott's donations dollar for dollar. Ed goes further for BSF by donating an additional \$500/month for each month his company is profitable. Ed is an important member of the BSF family.





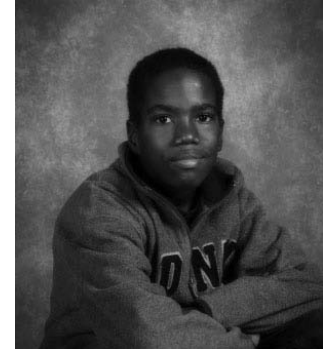
Abram, Age 2
Kansas, USA

Donations Made Easier

Donate via Check:

You may donate to BSF via check. BSF's headquarters is located at the following address:

Barth Syndrome Foundation
675 VFW Parkway #372
Chestnut Hill, MA 02467
Attn: Linda Stundis, Executive Director



Jeremiah, Age 11
Maryland, USA

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.



BSF is an accredited member of BBB

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."

In Loving Memory of Jamal Thomas



Jamal Thomas
August 23, 1984—December 23, 2009

THE LIFE AND TIMES OF MAL

BY JAMAL THOMAS

August 23, 1984—December 23, 2009

These slightly modified journal entries were read at Jamal's funeral service:

Part 1: Join me as I let y'all know about my life. Everything I am about to tell y'all is true and real. I be the boy Mal from South Philly. I am 24 years old and I will be turnin' 25 on August 23, 2009. I been dealin' wit a lot in my 24 years of life. I was born wit a heart disorder called Barth syndrome. It is a very uncommon health problem. Only boys can get this problem and some females carry the gene. There's a lot of other kids wit this heart problem. I was hospitalized at Thomas Jefferson on September 24, 2008 due to this heart disorder that I have. Everything was looking good for me and I was feeling better. I was getting back to myself. Then on September 28, 2008 things took a turn for the worst. I went into v tach, passed out and my heart had stopped. I flat lined. I kept going into

v tach. It happened about 4 times back to back. I passed away all 4 times. I saw Heaven and God but the last time they brought me back. I was in a coma for about three days. After I came out of the coma, I had all types of things that I was hooked up to. One thing for sure, my family was right there by my side and I know God was watching over me the whole time. I know it was not my time to go home. God kept me here for a reason and I thank God every day for that. I had to take time out for me to really get my health back on the right track. I always had time for God but I needed to take more time out and the things we talk about. I am so hyped right now 'cause God has a lot of blessings in store for me and I can't wait until that day. God blesses me every day just by letting me stay on this earth for 24 years and a lot more. One day in the summer of 2008, the summer was about to end and that's when the s.p.b. name started to pop over. We really get made love in our hood (South Philly). It's only two of us s.p.b. (myself and my big brother Byrd). I know y'all want to know what s.p.b. means. The meaning is self-proclaimed brother. Everything I just told y'all, that's the life of Mal and I will live my life to there's no more air in my body. It's 09 baby and the self-proclaimed brothers ain't stoppin'. I just want to take this time out to show love to everyone I lost in my life over the years. R.I.P. grandmom, aunt Mande, Jamil aka lil Grant, aunt D, Mr. DeWhite and many more of my homies I lost to the street life. I just want to let y'all know there is more of the life of Mal comin' real soon. It will not be a long wait. I can tell you that for sure. I'll get at y'all s.p.b. himself is lettin' everybody know.

Part 2: The self-proclaimed brother, Mal, is back wit Part 2 of the life of Mal. I gave ya'll part of Mal not too long ago as I told y'all about my heart disorder that I lived with for 24 years. Thanks to God and all my loved ones. On June 16, 2009, I was doing everything I do everyday, living my life, I was feeling good all that day then that night I was in the house talking to my family and then I just started getting' real short of breath and it was hard to get air out and my heart was beating really fast and I felt light headed so I had hooked myself up to my oxygen that I had in the house that I use from time to time if I need it. I was hooked up to that for a couple of minutes and it was not working so my mom called 911. Once the EMT's got to my house they did what they had to do and I started feeling a little better but they said I had to go to the hospital to be looked over and make sure everything was okay. They brought me to the ER at Jefferson. I was in the ER for a couple of hours. They did all the tests and other things and that's when I found out I have asthma like I need something else to deal wit. A self-proclaimed brother, Mal, is a fighter. I don't give up 'cause I know God will not give up on me, not now and He never will.

Photos of candles lit by Barth families from around the world in memory of Jamal.



In Loving Memory of Philip Brown



Philip Brown
May 22, 2005—September 29, 2009

The tribute below is taken from words spoken at Philip's funeral.

Philip was born in Harrogate to his parents Maike and Alan on 22 May 2005, with Barth syndrome.

In June of this year, his heart function was declining so he was admitted to the Freeman Hospital in Newcastle in readiness for a possible heart transplant. Philip waited seven weeks for a donor and took this experience in his stride, never once complaining—in fact at one point his father asked him if he was looking forward to coming home when he was better and he replied emphatically, “No, I like it here!”

On 15 August a suitable donor was found and Philip's transplant took place. The operation went well, but four weeks later with hopes high and on the brink of being discharged, he began to decline again and a few days later suffered

a cardiac arrest. For the last 13 days of life, Philip was heavily sedated on an ECMO artificial heart machine, his only hope being a second donated heart, but a suitable one was not found in time.

Philip was not particularly interested in conventional children's toys. He was more interested in elemental things like fire, water and wind. His old Victorian house had open fire places and he much enjoyed helping his father make a fire in winter. He also enjoyed holding a smouldering incense stick near the fireplace, when there was no fire, and watching the air currents carry the smoke up into the chimney. In fact, such was his interest in fire that his parents were slightly concerned that his chosen future career path might be arson! Waterfalls in the countryside and ornamental fountains in parks and shopping malls also captivated him and one of his favourite DVDs was a documentary about floods, hurricanes and tornadoes.

Philip liked Captain Jack Sparrow of the 'Pirates of the Caribbean' films—the gory bits did not bother him—and also Robin Hood. The hospital nurses sometimes had a hard time of it. If Philip was not waving his Jack Sparrow sword at them then he was either shooting them with a bow and arrow or he was a dragon, roaring fiercely and brandishing his sharp claws.

At nursery school he found physical things a bit difficult, because of his weak muscle tone. However, he did enjoy PE, and learnt how to do the 'Hokey Cokey' (which he liked to demonstrate to people).

He got pleasure from baking, both with his mother and also at nursery. While in hospital, Philip and the nurses prepared a fresh pizza and took it down to the main hospital kitchens. The head chef came out dressed in his full regalia and offered to bake it for him, and Philip was greatly impressed. The pizza was duly baked, and shortly afterwards returned to him on the ward food trolley.

Philip's favourite joke was to ask someone, “What do you call a deer with no eyes?”. When the reply was, “I don't know,” he would exclaim with gusto that the answer was “no-eyed deer.” We are not sure if he ever really understood his joke, but it pleased him to see the laughter that it produced in the person to whom it was told.

Fond memories from Claire Clements, Philip's child minder:

‘Philip was such a bright child in every sense of the word. He had a real thirst for knowledge which generated a seemingly endless supply of questions! His extensive and very expressive vocabulary amazed us all. Philip would sometimes use German words and was always surprised that I didn't understand, and would do his best to explain. His infectious cheeky smile, delightful sense of humour, and general enthusiasm made him a great person to be with, whatever your age, and earned him the nick name ‘Smiler’ from the older children.

Philip had a great imagination and loved to dress up and pretend to be different characters. We had a very memorable visit to the Chevin (our local wooded hillside) reliving ‘The Gruffalo,’ and Philip was so excited to be ‘climbing trees’ and hiding in the woods. At Philip's instigation, we would all sit under the dining room table and read stories in the dark by torchlight!

It has been a privilege to know Philip. We miss him so much, but the sadness is accompanied by so many fantastic, happy memories and photographs that we will never forget him.

There never has been and never will be anyone in the world quite like Philip.

Barth Syndrome Trust

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

IN OUR HEARTS ALWAYS

When faced with the loss of our children, all else seems to fade into insignificance. As I sit here writing about what we've done in the past few months, my only wish is that we could somehow turn back the clock and trade it all in. Exchange the successes and achievements and, in return, restore boys like Michael Telles, Philip Brown, Michael Bowen, Jamal Thomas, and all the other, equally beloved boys back to their families and thus back into our wider family.

We all work so hard and we strive to remain strong in the face of adversity. Why? We fight for the privilege of holding our children safe in our arms until we start to see the men they will be tomorrow in the boys they are today. As they grow up, the ties of the body become the ties of the heart.

We have had to say goodbye to some of our boys far too soon and, as a community, we have grieved with their families and we have been awed by their strength, their depth of feeling and their humanity. We will hold your sons in our hearts, always. The gift of joy they brought us all outweighs the grief they left behind. We are honoured to have known them.

Update of Activities

In addition to the emotional turmoil we have faced this year, we have had to operate within the global financial turmoil that has caused many businesses and charities to fail. In line with the challenges we were facing, we decided to consolidate our operations and focus on our core activities, to minimise unnecessary risks and new ventures. Instead, we would deliver what was expected, confident that we would ride out the storm and still be delivering in the years to come.

The trustees made their plans, concerned at the declining income figures. Volunteers' time was stretched as their focus often had to shift away from unpaid charitable work back to their paid jobs. Things were looking grim.

And then, something totally unexpected happened. Just at the darkest hour when all seemed a little hopeless, tales started to trickle in. Families and volunteers from all over the UK and Europe were all doing fundraising, making personal donations, supporting the registry, attending the clinic, helping other families, volunteering. Making a difference.

We had set up this charity fully expecting to give our families what they needed. In other words, this was a place where it was okay to take. But when I happened to glance around the room during a slight lull in the clinic activities, I was struck by the realisation that there was not a single person who was taking more than they were giving. Quite the reverse. Just at the time when we individually felt alone, here was the irrefutable evidence that we were not alone anymore. Since its inception in 2003, I have never seen such a spirit of comradeship and cooperation within the wider BST community as I've witnessed this past year.

And so I thank every one of our families, medical staff, scientists, volunteers and donors. In the following few pages, we'd like to highlight some of your efforts and show what an amazing difference adding your part has made to the big picture.

Bristol Clinic

The annual Barth clinic at the Bristol Royal Hospital for Children was held on 18th September 2009. A total of 17 affected boys and young men attended, along with their families. As always, we strive to make this meeting as informal and informative as possible. Families get the opportunity to meet each other and the children have great fun as they literally have the run of the entire Play Centre for the day. There is also the much valued chance to have one-to-one appointments with specialists like Dr. Colin Steward, Dr. Bev Tsai-Goodman and Dr. Ruth Newbury-Ecob, to name a few. Here you can go over the intricacies of your child's care on an individual basis. A full cardiac work-up is carried out too.

(Cont'd on page 23)



*Families gather at the Bristol Clinic.
Photo courtesy of BSTrust ~ 2009*

(Cont'd from page 22)



Photo courtesy of BStTrust ~ 2009



Photo courtesy of BStTrust ~ 2009

The afternoon sessions this year included a talk from Dr. Ann Bowron, Senior Biochemist at Bristol Royal Infirmary, about the role of cardioliplin in Barth syndrome.

This was followed by a presentation from Dr. Newbury-Ecob on the genetics of Barth syndrome, as well as prenatal testing options for Barth families who are thinking about having more children. Dr. Tsai-Goodman then focused on cardiac issues in Barth syndrome, explaining clearly how the heart functions, how a fractional shortening or ejection fraction is calculated during an echocardiogram, and what treatments are available for cases of cardiomyopathy.

After an emergency evacuation which caused a certain amount of disruption with half the group standing on the roadside outside the hospital and the other half in the Play Centre courtyard, the all clear signal sounded. The afternoon ended with an open question session hosted by Dr. Steward during which varied topics were discussed. Examples include the H1N1 vaccine and signs and symptoms of sepsis.

The clinic would not be possible without the dedication of many of the staff at the Bristol Royal Hospital for Children. Special thanks to Dr. and Mrs. Steward, Dr. Tsai-Goodman and their teams, as well as staff of the Play Centre.

The clinic is a much needed way of gathering data about all the UK children and young people. As such, it does mean that the boys have a hectic schedule of ECGs, echocardiograms, blood tests, physical examinations, etc. However, our motto (and I know this is echoed by Dr. Steward and the team in charge) is that we have to strike the right balance and do all we can to make sure that the clinic is first

and foremost an enjoyable day for the children. I know that my boys (Nick, age 11, who has Barth syndrome and Matthew, age 7, who does not) both adore the clinic. They can't wait to meet the other children again—they love the experience of all staying overnight in the hotel, enjoying meals and play times together. And a day off school too—bonus! We look forward to seeing you all again in 2010.

Family Gathering

BST paid for a night's accommodation at a Bristol hotel which allowed families to stay over and enjoy a chance to relax and unwind over dinner. The following day, we all gathered at a nearby sports club, ordered in traditional fish and chips as well as a truckload of pizzas, and let the kids get on with playing skittles and pool. We hired in The Playbus—a traditional double-decker bus that has been converted into an indoor play paradise for the younger children. The variety of entertainment on offer, the delicious lunch, and the relaxed and informal atmosphere all made for a valued opportunity to connect, talk and play, far away from the traditional hospital environment. Many thanks to Sarah and Dave Bull and Tracy Woodward for organising this enjoyable day.



Boys during the Bristol Clinic and Family Gathering. Photos courtesy of BStTrust ~ 2009

A Big Thank You From the Barth Syndrome Trust...

to all of our supporters, families and friends who have worked hard and imaginatively in difficult times to raise a staggering total of £32,000 in 2009. Encouraging donors to Gift Aid their donations added another £558. Highlights of events since our last newsletter in April include:

England

Dave Baber, friend of sisters Sarah Bull and Tracy Woodward, and Les and Maxine Brooker of the White Horse Pub, Hambrook, Bristol, organised a whole day of fun including dinner, auction, hog roast, raffle, live band and other creative money spinners.



*Russell Osmond auctions autographed celebrity football shirts.
Photo courtesy BSTrust ~ 2009*

The marquee and tables decorated by Maxine looked beautiful in BSF blue with vases of exotic flowers. Sarah made a very moving speech about Barth syndrome. Russell Osmond conducted the Auction which included autographed celebrity football shirts raising more than £5000. A brave man challenged the crowd to sponsor a hair shave and lost his locks for well over £300! The day's total of £8789 exceeded all expectations. Sarah says, 'We can't thank Dave Baber and the Brookers enough.'

In June, Fiona Carretas and her class at St. Francis of Assisi School, London, baked and sold cakes to raise £136. Well done girls and boys.

Terri Allison (with Cynthia Condliffe and other local volunteers) organised several events, including a Nearly New Sale, a Car Boot Sale and a Race Night, raising a total of £562 and inspiring others to venture into fundraising.

Sarah Whithorn and her family raised £300 from a tombola, which was fully matched by Barclays Bank.

Another sponsored walk by Roger Atkins raised £100.



*Autumn concert by Beech Hill Concert Band.
Photo courtesy BSTrust ~ 2009*

Anne Ward held a Coffee Morning, Bring and Buy Sale and Raffle. She organized an Autumn concert by the Beech Hill Concert Band which brought music to everyone's ears and the total profit to £1241. Thank you to the Basingstoke Unicorn Club for sponsoring the concert, to Constellation & Matthew Clark, Bristol for the wine, and St. Bede's Church.

Friends of Nick, Katie and her mum Laura, once again walked part of the Test Way and held a garage sale.

Bring and Buy Sales at the homes of Maike Lange and Alan Brown, and their friend Sima Goldsmith raised £468. At William Cook (Leeds) Ltd., a collection box raised £161. Some box!!

The Greens, our newest family, raised £500 from a bingo session at their home.

A food quiz organised by Gill Amos (whose son has Barth syndrome) and her mother, Margaret Amos, raised over £400.

(Cont'd on page 25)

(Cont'd from page 24)

Ireland

£3000 was raised in Celbridge, near Dublin, Ireland in October. The grandparents of a boy with Barth syndrome, Pat and Roy Craigie, helped by Pat's friends, hosted an evening salmon buffet. Val and Hazel Craigie held a coffee morning. These happy events have raised awareness of Barth syndrome in Ireland, which as far as we know has no diagnosed Barth boys.



*Roy Craigie enjoys the Coffee Morning.
Photo courtesy BStrust ~ 2009.*

Scotland



*Jay, Alfie (BTHS) and their friends raise £91 for BST.
Photo courtesy of BStrust ~ 2009*

Jay, Alfie (BTHS) and their young friends raised £91 for BST. Ciara (age 8) sold raffle tickets, and then Ciara, Lauren, Naeve, Shannon, Jay and Alfie put on a show including dance routines, magic, singing, a comedian, violin pieces and Jay on the guitar, and raffle. They did everything themselves, including making tickets and posters, and cakes and lemonade for the interval.

The parents of Alfie and Jay sent a cheque for £1005, proceeds of another successful run in the Glasgow Half-Marathon by Tommy, who twisted the arms of workmates at the Dunlin Alpha Platform, and the selling of hidden team scratchcards by Allanna. Claire McAteer, Tommy's cousin, ran the Glasgow Women's Road Race in record time in May and the Glasgow Half-Marathon, raising £190 and awareness at the same time.

BG Group, along with AMEC, Dolphin Drilling and Cape, donated £1400 as part of an accident prevention scheme after workers on an oil platform

in the treacherous North Sea completed an incident-free week. Many thanks to Lawrence Salmon, uncle of two boys with Barth syndrome, who suggested BST.

BAE Systems Prestwick's Charity Golf Challenge for employees, customers and suppliers raised £650. Thank you to BAE Systems and John Anderson, friend of an affected family, for nominating BST.

Static Collection Boxes

£2100 was collected by Dave Bull, Pete Craigie, Julie Woolley, Maike Lange, Lorna Moore, Helen Coleman, and Jérôme Doherty-Bigara.

Celebrations

Thank you for the generous donations from guests at Gil and Rosemary Warner's wedding, Barry's birthday bash, and Michaela's salsa party.

Standing Orders and Donations

Large single donations from organisations and families in UK and Europe have also given a tremendous boost to the Trust. Altogether, we have received £5429 from single donations and standing orders since January 2009.

How can we best use this money?

The Trustees recently decided that some of the money you've raised will be spent on funding an approved scientific grant. Money will also be made available for targeted doctors, researchers, and families to attend the 2010 International Barth Syndrome Conference. Many thanks for making this possible.

Adieu to our Treasured Treasurer

Jérôme Doherty-Bigara

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



*Jérôme Doherty-Bigara.
Photo courtesy BStrust ~ 2009*

I first met Jérôme in South Africa in 1987, when we both started university together and the terrible food in the university accommodation made him flee to our house where the food was considerably better! His parents knew my parents, and so began a new generation of friendship, between him and me—one that has survived over 20 years of amicable arguing about every imaginable topic. I am fortunate to count him as a loyal friend, and even more fortunate to be able to always count on him whenever I need him.

And so, in 2003, he was the first person I turned to when looking for a Treasurer for the newly-formed Barth Syndrome Trust. His qualifications (MBA from Cranfield School of Management), his experience as a facilitator and consultant in the arena of global leadership, strategic and change management, team building and development, post-merger integration and learning expeditions for senior executives, together with his business acumen, made him an ideal candidate for the job. His love for my son, Nick, who has Barth syndrome, clinched the deal. Here was the ideal mix of someone who cared deeply about the boys we serve and who had the skills needed to set the charity on a path to success.

In the past six years, Jérôme has served all our community by stretching everyone to continuously plan, prioritise and then deliver. In the early days when we were all thinking small and safe, he was already challenging us to think bigger and bolder, whilst still ensuring the safety of the Charity's good name and financial standing. Most of the families have never met him—his role has been a background one and he has never sought any public recognition. However, we all owe him a huge debt of gratitude for his years of service to BST. Jérôme will continue to serve as an external advisor, but, due to his challenging work commitments which take him abroad for most of the year, he is stepping down as Treasurer with effect from November 2009. On behalf of our community, I'd like to extend our thanks and gratitude for all his commitment and hard work over the years. Jérôme hands over the baton to Gemma Wilks, who has already proven to be another excellent candidate for the role of Treasurer. Gemma, who is a Chartered Financial Accountant, has been a trustee since October 2008, and has been working alongside Jérôme to date, thus ensuring a seamless handover. Best of luck to you both.



Fantastic Holiday with CHF

By Oliver (17 Years Old), United Kingdom



*Oliver (right). Thumbs-up for dirtbuggy driving.
Photo courtesy of CHF ~ 2009*

The trip to Portugal organised by the British Children's Heart Federation (CHF) during August was amazing! A group of ten teenagers with heart conditions flew to Portugal for a five-day activity holiday including me, Ollie, one of the Barth boys. With the support given by CHF staff, we were able to take part in many awesome and physically challenging activities. These activities included canoeing, kayaking, caving, dirt-buggy driving (fantastic!) and raft building, plus a range of mini activities.

For someone who has eating difficulties, I found Portuguese food interesting and tasty—with everything we did working up a great appetite. The best thing I got out the trip is exactly what I wanted: to go to Portugal to make new friends, experience independently a beautiful country with beautiful weather, and sample a little Portuguese culture. During the trip I took some fantastic pictures of fantastic people to remember a fantastic holiday.

I would like to thank Annick Manton for nominating me for this opportunity and all the staff at the British Children's Heart Federation for making it such an amazing trip.



Barth Syndrome Foundation of Canada 2009 Successes

By Chris Hope, Lois Galbraith and Les Morris, Barth Syndrome Foundation of Canada

This article is being written shortly after Thanksgiving—a time during which families get together, and a moment is taken to reflect on our good fortunes. As a Foundation, we take the time to look back and review our accomplishments and activities over the past few months. When going over our events we are always astounded at the progress that has been made and what we have learned in such a short time frame. At this time last year, the BSFCa executive was planning programs and actions for 2009. We were, of course, very aware that we would be facing a difficult year, and we deliberated accordingly. We knew that although we would be trying to grow the organization, we would mainly be relying on existing donors and volunteers to carry us through. We are very fortunate to have loyal and enthusiastic volunteers who continue to give us their time, expertise, encouragement and ideas. It is because of those volunteers and donors, all of our expectations for 2009 were either met, or greatly exceeded what we predicted.



BSFCa executive—still smiling at the end of the golf tournament!



Awareness

One of our ongoing efforts year round is to spread knowledge of the syndrome wherever we go. Many of our families have taken to carrying Barth bags or Barth bears with them when they are shopping, at restaurants, or on vacation. People always want to know why you are taking a picture of a bear with a hand knit sweater with a 'swirly thing' on the front. Our volunteers support this project by knitting sweaters with the Barth logo and putting them on teddy bears which we hope people will take around the world with them.

Spreading the word to the centre of North America

Cathy Ritter and Chris Hope travelled to Ottawa, Canada for the Canadian Paediatric Society conference. This was a one day exhibition which included paediatricians in different specialities from all over the country. We have never had such an enthusiastic and inquisitive crowd come to our booth. Our new brochure was very well received, and many questions were asked concerning diagnosing and treatment options.

The day after the conference, we met with doctors at the Children's Hospital of Eastern Ontario, and they assured us that they would spread the word and keep their eye out for any of the cardinal signs of Barth syndrome.

For some time we have wanted to overhaul our website, and we are now happy to report that we are working on the final design and that the new site should be up and running shortly. We hope that this site will be easy to navigate, provide benefits to our existing families, and hopefully encourage new families to contact us. We invite everyone to check it out at www.barthsyndrome.ca.

(Cont'd on page 28)

Barth Syndrome Foundation of Canada 2009 Successes

(Cont'd from page 27)

Research

We are pleased to be able to continue funding scientific research grants. This year we have pledged to partially fund a grant entitled *The role of tafazzin in mitochondrial protein import—implications for Barth syndrome*. Principle Investigator: Miriam Greenberg, PhD, Wayne State University Detroit, MI.

Family Services

Our families and affected individuals remain a major focus for us, and we continue to encourage, inform and advocate for them as much as we can, whenever necessary. Individuals and families have received additional information and brochures for their Resource Binders, and we hope that they find them positive and practical and that they are able to make good use of them. We would be happy to receive any feedback and as well encourage recipients to give us ideas for additional topics.



Fundraising

Our fundraising efforts over the year have been very successful again, exceeding our budget in every regard. We had a great response to our yearly mail appeal, and people have now started collecting and donating their coins year round. We have been very fortunate in the ways and means that donors have found to give to us financially. Some chose to donate monthly, others hold private fundraisers on our behalf, which has been everything from collecting bottles to holding parties or silent auctions, and Cathy Ritter is getting ready for her yearly event selling poinsettias.

We have been privileged to have several major donors who hold BSFCa in a special place in their heart and who truly believe in us and our mission. We are sorry to say that one of those donors recently passed away. Although he never wanted any acknowledgement, for the past few years whether we needed funds or business advice, we knew that we had a special friend we could turn to. We are truly grateful for his assistance and for the forthright manner in which he gave it. During the last few months of his illness, when it could be expected that someone would think only of himself or his family, our special friend made an extra effort to remember us with another donation. We are truly appreciative, and will miss our benefactor greatly, not only as a donor, but as a friend.

Planning for 2010

We now have to start thinking about where we want to go and what we want to do for next year. Once again, Les and Lois have offered the BSFCa executive their home on Lake Kasshabog, ON, Canada for our strategic planning weekend. Susan Hone will be flying in from Regina, SK, and together we will consider all of our programs and figure out where our focus should lie in order to best forward our mission.

As well as working on our actual programs and goals, we continue to work behind the scenes organizationally to make sure we have a strong Foundation, which ensures our future. Our special thanks goes out to everyone involved in making the year 2009 more successful than we could have imagined.



Newsy Notes from our Canadian Barth Guys

Every year our Canadian donors and volunteers ask us; “How are your Barth guys doing?” We have responded to this in our Canadian newsletters in a number of ways without detailing medical prognosis.

We polled the guys and they were willing to let people who read the international journal know how they are doing. We agreed and their comments are noted below.

Sheldon is eight and a half years old and is in Grade 3 at Niagara Public School in Toronto, Ontario. He enjoys all sports, but particularly likes hockey and soccer. He continues to play the piano well.

Liam is in Grade 8 at Maple Grove School in Yarmouth, Nova Scotia. He is drumming at school and has joined the Memorial Club—a club where members visit and celebrate with our veterans.

Travis is fourteen and entering high school next year. He continues to play guitar and sounds amazing. Another hobby that he enjoys is photography. He loves the outdoors and enjoys fishing with his Dad.

Jared is fifteen and in Grade 10 at Campbell Collegiate in Regina, Saskatchewan. His extracurricular activities include swimming and music therapy. He loves family get-togethers and is the proud Uncle to Abby and Oliver. He was recently in the local newspaper advocating more family-friendly wheelchair accessibility.

Ryan is currently in Grade 12 at Bear Creek Secondary School in Barrie, Ontario. He enjoys reading and archery. He is also involved with the ‘Link Club’ (helping junior students adjust to high school) and the ‘Free the Children Club’ at school.

Adam is in his second term at Fleming College, Lindsay, Ontario. Attending school and studying takes up a great deal of his time, but he still enjoys tinkering with his tractor and car at the cottage and at home.

Robert is currently working at the family business in Mississauga, Ontario. He has masterfully represented the Barth Syndrome Foundation of Canada at a number of events. At the moment his main hobby is writing.

As you can see, it is obvious that our Barth guys have a tremendous variety of skills and interests. We wish them well.



Volunteering ... *Bob's Birthday Bash for Barth*



*Bob's birthday bash for Barth.
Photo courtesy of BSFCa ~ 2009*

An organization such as the Barth Syndrome Foundation of Canada (BSFCa) has fantastic and innovative friends and volunteers. They email us with ideas and their suggestions flow at our volunteer meetings.

This year Bob McJannett, volunteer extra-ordinaire, turned seventy years young and wanted to have a street party with a live band. He convinced his wife Susan to pay for the band as her gift to him. He now had the date, the band and a reason to party with friends.

Bob took care of all of the details, made lists and made sure he invited all of his neighbours. He was excited about the plans and motivated to help the BSFCa. Bob insisted that there be no gifts. He did however, on his invitation, ask for donations to his favourite cause, the Barth Syndrome Foundation of Canada.

The lead singer was George Olliver from the 1960's band *The Mandellas*. The music was upbeat, loud and perfectly suited to Bob's era of friends. George sang through three sets and had friends singing along and dancing in the gazebo. He also stayed on at the end of the sets to socialize with Bob's guests. It was a memorable evening, and we thank Bob and Susan for their great birthday plans, their dedication, and of course their generous donation to the BSFCa. Happy Birthday Bob!!



BSFCa 2009 Golf Glory and Gains



Loyal golf supporters Lynn Elwood, Henk Alblas, Beth Conway and Gwen Tjart.

In spite of these days of tight budgets and careful spending, our BSFCa sponsors and golfers came through for us again.

Our 5th Annual Barth Syndrome Foundation of Canada Golf Classic was held on Monday, September 14, 2009. The weather was sunny and perfect. The golfers were loyal, happy, and generous. Our hole sponsors numbered thirty and our prizes donated were in the hundreds. Our major sponsors, Hope Aero, IQI – Ian Morris and the Buss Megg Society were with us on this year's journey again.

The stage was beautifully set for a great day! Our volunteers arrived full of enthusiasm and verve. We all rolled up our sleeves and prepared for the day. Robert, one of our Barth young men, made a fine presentation to the club's tournament director and

the carts were off to their proper holes for a shot gun start. The course was in excellent shape and our golfers were appreciative. There was much fun and comraderie all day.

A lot of shenanigans went on at the putting contest, and even with the people running the event giving helpful hints, very few of us were inside the target area or in the hole. As well, the details surrounding the tail gate party in the parking lot were sketchy enough to let you know that a good time was had by all involved.



Golfers Ken Weeks, Byron Tyers, Steve Kemp, and Robert Tyers.

The supper and evening program flowed smoothly. People bid on silent auction items and bought tickets on our two raffles. Each golfer chose a gift from the prize tables and we presented awards to our sponsors and some outstanding golfers. The raffle of a Napoleon BBQ was won by Steve McGill, and the week at a condo in South Carolina was won by Paul Gilmour.

We thanked everyone again and gave them the date for the 2010 tournament. Special thanks went to Jan Kugelmann, Sharon Olsen and Joanie Weaver of Merritt Island, Florida for making the long trip to add sparkle and an international flair to the day.

All the goodbyes, hugs, and yes, the clean up, went smoothly. We were relieved and ecstatic with the day and with the friendship and support of golfers, families and friends. Months of work organizing and gathering had made for a glorious golf day again. The final tally showed that we raised \$25,500.00—our best ever!



Vicki, Robert and Penny run the Putting Contest!



Lynn Elwood thanks the golfers for a great day. Photos courtesy of BSFCa ~ 2009



Sibling Spotlight

Featuring friends from around the globe

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



Name: Olivia

Age: 10

Where are you from? I live in Highland Lakes, New Jersey.

What are your hobbies? I enjoy swimming and playing soccer.

Affected siblings? Jack (age 16)

What do you like doing with your brother? Jack loves to cook, and I enjoy baking chocolate chip cookies with him.

If you met someone who had just found out that their brother had Barth syndrome, what would you say to make them feel better? I would tell them to check out the fundraisers and go to the meetings to learn more about Barth syndrome. I would also tell them to be there to help him out since there are things he can't do like everybody else.

What does BSF mean to you? It helps my family understand what my brother has and what is affecting his heart.



Name: Lauren

Age: 23

Where are you from? I was born in Durban, S. Africa, although I am currently living in Scottsdale, Arizona.

What are your hobbies? I love reading, and horses have always been my passion, much to my mother's dismay. I enjoy yoga and dancing, as well as just relaxing with friends. I do a lot of studying, although that's not really a hobby.

Affected sibling? Colin (age 13)

What do you like doing with your brother? Colin LOVES play station, and he is REALLY good at it. We have a Samuri game we play together, but all of my friends know that they have the one game rule if ever they visit, that means that Colin gets them for one game. I love taking him to play miniature golf. It's such an adventure, and I don't know who has more fun!!

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 say that my little brother is one of the best things to happen to our family. He is such a precious and loving person! He has taught me so much, and he continues to teach me the older he gets. I think that he has matured a lot faster than many other boys his age. I would say that all the Barth boys are precious blessings, keep them close, learn from them, and enjoy every moment you have.

What does BSF/BTrust S. Africa mean to you? It is a valuable source of information and support. It provides a platform for networking, and it lets you know that you're not alone.

Power of Kindness

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WHAT IS BARTH SYNDROME?

Barth syndrome (BTHS; OMIM #302060) is a rare but 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 multi-system disorder often include combinations and varying degrees of:



Photo courtesy of Amanda Clark ~ 2008

Cardiomyopathy

(Dilated with variable myocardial hypertrophy, sometimes with left ventricular noncompaction and/or endocardial fibroelastosis)

Neutropenia

(Chronic, cyclic, or intermittent)

Under-developed skeletal musculature and muscle weakness

Growth delay

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

Exercise intolerance

Cardiolipin abnormalities

3-methylglutaconic aciduria

(Typically 5 to 100-fold increased)

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