



**Barth Syndrome
Foundation**

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

2014 BSF Conference — The SciMed Sessions

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

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Matthew Toth, PhD

Over 330 people attended the 7th International Scientific, Medical & Family Conference on Barth syndrome, held at the Hilton Clearwater Beach Resort in Clearwater, Florida on June 23-28th, 2014. Seventy five of these attendees were researchers, physicians, and healthcare professionals making it the largest scientific gathering dedicated to discussing Barth syndrome ever convened. The Scientific and Medical sessions (SciMed) were held over two days and included 22 speakers covering topics such as: Mitochondrial Lipids, Clinical Studies on Barth Syndrome, Mitochondrial Physiology, and Animal Models. A Poster Session took place on the evening of the first day, and four poster authors were selected to speak about their work. The 2014 Conference was hailed as an outstanding success by individuals with Barth syndrome, family members, clinicians, and researchers. More than half

of the SciMed attendees indicated this was their first Barth Syndrome Foundation (BSF) Conference, and more than 95% stated they would attend a future conference. This demonstrates that interest in Barth syndrome has expanded for researchers and clinicians which, in turn, will lead to even more progress in combatting this disease.

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The Barth Syndrome Foundation and Cardioliipin Research in Italy

By Daniela Toniolo, PhD, San Raffaele Scientific Institute, and Angela Corcelli, PhD, University of Bari Aldo Moro, Bari, Italy



Dr. Daniela Toniolo

The TAZ gene, encoding for an acyltransferase involved in the cardioliipin metabolism, was discovered in Pavia, Italy in 1994. Nevertheless, Barth syndrome has been a very neglected and under-diagnosed disorder in our country. Few patients and families are recognized and most (all of whom live in central Italy) were diagnosed in Florence at the Meyer Hospital by the group led by Dr. Maria Alice Donati. They all live in central Italy. A couple of years ago one of us, Dr. Daniela Toniolo, was contacted by a mother, Dr. Paola



Dr. Angela Corcelli

Cazzaniga, who was looking for other families to share difficulties, ideas and problems. Her son was the first diagnosed in the north of Italy but still at the Meyer Hospital and only when he was 10 years old and after two other affected sons.

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When Large Research Gets a Cold, We Get Pneumonia

By Lindsay Groff, Executive Director, Barth Syndrome Foundation



A recent report on National Public Radio explained how the decline in funding from the National Institutes of Health (NIH) has hobbled scientific research on a national level. The report stated that scientists are spending more time searching for grants than working towards treatments or cures. In this new environment, important progress can come to a screeching halt. This is tragic!

I asked our Science Director, Dr. Matt Toth, how these cuts affect the Barth Syndrome Foundation (BSF). He noted, "Organizations in the rare disease community, like BSF, are struck twice as hard as much larger organizations." After thinking about my question, he further stated, "When large research gets a cold, we get pneumonia."

When government funding is tight, it is even more important to fund research privately for diseases like Barth syndrome. Private funding comes through donations from people like YOU.

Your financial support is making a huge difference in the lives of our boys and men. Now, more than ever, our small foundation is helping financially-strapped researchers continue their transformational work.

Dr. Miriam Greenberg explained how funding through our research grant program helped her attain a highly-coveted NIH grant in the last issue of the newsletter: "During this very bleak funding climate, support from non-federal sources is often crucial for scientists to test new hypotheses and develop new paradigms that may lead to important breakthroughs in medical research. Support from BSF has enabled me to carry out Barth syndrome-focused research that has led to subsequent NIH funding."

Without our Research Grant Program, funded through your generous donations, we would not have proposed clinical therapies on the table like bezafibrate. In fact, we would have little to no research on Barth syndrome at all. Researchers can only work on projects that receive funding, no matter how interesting or promising.

But, there is good news... while NIH funding is decreasing, this is still one of the most exciting times for Barth syndrome research. Our grant program continues to attract outstanding researchers and stimulate newsworthy research. Take Dr. Bill Pu's recent work, "Heart on a Chip" which was cited in Popular Science, for example. Even though we are a small foundation, we are making an amazing impact on Barth syndrome, with your help.

Never before have we had actual therapies to consider! This latest cycle of grants is predicted to provide several promising projects. These grants are a vehicle to get us one step closer to finding answers to the problems facing affected boys and men.

We're at a time where we need your financial support more than ever to keep our promising research moving forward as fast as possible. As you will see in other articles, we have made incredible progress. We need your help so that life-saving research on Barth syndrome does not end. If there was ever a time we needed your financial support, now is that time.

Thank you for your support.

One Path to Becoming a Board Member

By Marc Sernel, Chairman, Barth Syndrome Foundation

How did I get here? Becoming a member, and now Chairman, of the Barth Syndrome Foundation (BSF) Board of Directors was never on my list of career goals, even after I found out my son had Barth syndrome. I think it's fair to say that I did not seek out or do anything to lobby for the position. But here I am, and I'm proud to serve the organization in this capacity. I know a lot of people in our larger Barth community sometimes wonder how the people on the Board got there (and maybe wonder "how do I get there"). To give you some insight, let me tell you a little bit about my journey and some information about our Board more generally.

I remember coming to my first conference in 2006, within a month or so of receiving the diagnosis of Barth syndrome for my son. The cliché of "deer in headlights" probably described me to a tee. I was welcomed by all of these warm people I had never met before. I recall sitting in a circle at the welcome event, looking around and thinking "how did I end up here?" And I still occasionally wonder how I went from that naïve father to Board Chairman.

The journey into the world of Barth syndrome can start with unknowing and confusion and "why me" and anger and sorrow and despair. It is difficult to see hope when amidst the fog of parenting a sick child. Even the initial diagnosis of Barth syndrome is scary, and the fog does not lift right away. But BSF can be the sun that burns off that fog. BSF helps affected families cope. BSF is a source of information, a source of hope, and a lot of other people that just "get it." BSF is the driver of medical research for an eventual treatment/cure and best practices for caring for our boys and young men. I saw in BSF what I think many of our families see — the best chance to make a difference for the health and quality of life of my affected son.

So when I was approached by then-Chairman Steve McCurdy to get more involved with BSF, I gladly stepped forward. I say gladly, but it was also with some reluctance. I had a very demanding job, three young children, what already seemed like more than a full plate of commitments. But this was important so I "made the time." As someone with both legal and scientific training, I started out by looking at some agreements and advising Steve and the organization on issues that arose. In addition to donating my time and expertise, my wife and I also donated money to the organization. One thing led to another, including some interviews with other Board members for them to get to know me, and I was offered a position on the Board in early 2009.

I recall going to my first Board meeting and feeling like the new kid on the block, feeling like everyone else there had been running this organization seemingly forever. What I learned was that they were just a few steps further down the BSF journey than I was. As I became more involved with the mechanics of BSF I became even more impressed at how such an amazing organization is operated as a result of the efforts of a precious few. I slowly evolved from being the new kid to a veteran contributor. And after participating on the Board for three years, my fellow Board members then elected me Vice-Chairman and a year later Chairman of the organization.

So what does it take to be a Board member? An unwavering commitment to the mission of the organization. A willingness to contribute time, effort, and talents to our cause. An openness to differing viewpoints and an ability to disagree without being disagreeable. We do have a requirement in our by-laws that 50% of our Board members have a family relation to someone with Barth syndrome, but we also want non-family Board members as well. Now that I've told you what is required, what is not required? There are no minimum qualifications or particular pre-requisites. You don't need a fancy degree. The BSF Board, like all Boards, does benefit from having members that can assist with important functions such as finance, accounting, legal, and fundraising. But we need other skills too. We need people that know what it's like to be an affected individual or the parent of one. We strive to have a diverse Board, so that all of our constituencies — affected individuals to affected families to donors to doctors to researchers — have a voice as to the direction the organization will take.

Not everyone can be a Board member, but everyone can help our organization make progress toward its goals. We need you. We need everyone. We are too small to leave resources untapped. Please reach out if you are interested in learning more about Board membership. We are always looking for our "next generation" of leadership and you can be a part of it.

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2014 BSF Conference - The SciMed Sessions

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As in previous years, there were separate programs formulated for families or for scientists/physicians. Nevertheless, both groups mixed and shared mealtimes, the Clinical Studies session, the Poster Session, and the Friday night social event, which made for an enjoyable, educational, and inspiring event for everyone. These international conferences are sponsored by BSF and its affiliates, and the SciMed sessions were specifically supported, in part, by a R13 grant from the National Institutes of Health (NIH).

Thursday, June 26, 2014

The morning session focused on mitochondrial lipids and concentrated on the unique lipid associated with Barth syndrome—cardiolipin. A new understanding of the physiological roles for this unusual lipid was discussed which included exploring specific therapeutic ideas. Presentations by Dr. Valerian Kagan (University of Pittsburgh, PA) revealed how he is using music to easily identify slight changes in lipid composition, and by Dr. Miriam Greenberg (Wayne State University, MI) and Dr. Matthew Baile (Johns Hopkins, MD) who use yeast genetics to find out how other genes may alter the cardiolipin defects of Barth syndrome and to postulate that cardiolipin may act as a shield against oxidative damage to the mitochondria. Dr. Matthew Gillum (University of Iowa, IA) spoke about how another phospholipid is altered in Barth syndrome, and Dr. Angela Corcelli (University of Bari, Italy) presented a sophisticated technique (MALDI-TOF) that can fingerprint lipids for rapid Barth syndrome screening. Dr. Jun Zhang (Pennsylvania State University, PA) discussed how another gene involved with cardiolipin can alter the cardiomyopathy we see in Barth syndrome.



Dr. Valerian Kagan



Dr. Miriam Greenberg



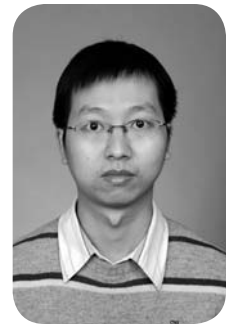
Dr. Matthew Baile



Dr. Matthew Gillum



Dr. Angela Corcelli



Dr. Jun Zhang

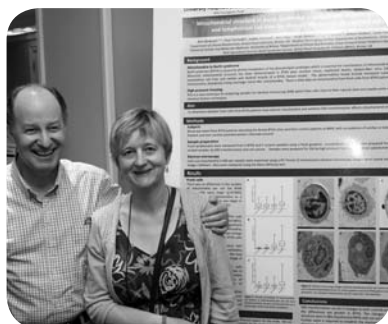


Dr. Barry Byrne at Keynote Address.

At noon, Barry J. Byrne, MD, PhD, delivered the Keynote Lecture on orphan product development in this era of personalized medicine. Dr. Byrne is a renowned pediatric cardiologist, Director of the Powell Gene Therapy Center at the University of Florida, and a major champion for finding treatments for individuals with rare diseases. He has been a particularly close friend of BSF over the years.

The afternoon session focused on clinical studies, and it included encouraging reports from the two clinics, on different continents, specializing in the care for Barth syndrome individuals.

Dr. Colin Steward (Bristol Royal Hospital for Children, UK) provided insightful lessons from the Bristol, England Clinic (which has been operational since 2004 and has been officially supported by the National Health Service of the United Kingdom since 2010). Prominent among his suggestions were the importance of establishing a multidisciplinary clinical team to care for Barth syndrome individuals, and the avoidance, wherever possible, of the tendency to “subcontract” medical care to specialists working in different areas. In a disease that affects so many tissues and organs, this can result in affected boys/men having unmanageable numbers of consultations with negative consequences for their schooling or employment. In addition, there is a definite benefit in having the older boys/men with Barth syndrome interact with their younger peers in clinic and non-clinic situations.



Dr. Colin Steward and Ann Bowron at the Poster Session.

Importantly for the BSF community, Dr. Steward and colleagues have received preliminary support from the UK's National Institute for Health Research to clinically study whether bezafibrate treatment may be therapeutic in Barth syndrome. One colleague of Dr. Steward, Ann Bowron, FRCPATH, reported on a subgroup of Barth syndrome individuals whose cardiolipin dysfunction

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levels are intermediate between the biochemical values of the unaffected population and of other Barth syndrome individuals. This unique Bristol subgroup appears to be less affected than others with this mitochondrial disease. Details of this intermediate phenotype have now been published as an Open Access article available via BSF's website (Bowron et al., J. Inherit. Metab. Dis., August 12, 2014).

Dr. Hilary Vernon (Johns Hopkins University, MD) reported on the clinic established for the last two years at the Kennedy Krieger Institute in Baltimore, Maryland. Dr. Vernon presented and discussed the biochemical profiles of Barth syndrome individuals which showed: increased 3-methylglutaconic acid in plasma; increased urine levels of organic acids; lower pre-albumin, arginine, and cystine levels in plasma; higher levels of tyrosine, proline, and asparagine in plasma; and unremarkable cholesterol levels. None of these individual biochemical values correlated with age or with each other or with neutrophil counts (neutropenia or a low white blood cell count being a common symptom of Barth syndrome). In addition, the Baltimore clinic also performed an analysis of the female carriers of Barth syndrome who do not normally display any symptoms, and they could find no biochemical abnormalities.

Dr. Jean Donadieu (Trousseau University Hospital, France) updated the group about his efforts to gain recognition of Barth syndrome in France, assisted by the BSF affiliate, Association Barth France. Dr. Donadieu and colleagues have published a retrospective analysis of the French experience with Barth syndrome which is available as an Open Access publication also found on BSF's website (Rigaud, et al., Orphanet J. Rare Dis. 2013).

Dr. Todd Cade (Washington University, MO) reported on his metabolic studies supported in large part by his R01 grant from the NIH. In preliminary data with stable and radioactive tracers, under resting, exercising, and recovery periods, it appears that Barth syndrome individuals show lower palmitate oxidation, increased protein breakdown (but not oxidation), increased glucose uptake (but not oxidation), and increased lactate production.

Dr. Stacey Reynolds (University of Florida, FL) spoke about her investigations into the taste and feeding behaviors of Barth syndrome individuals. Dr. Reynolds confirmed the salty-cheesy food preference in Barth syndrome individuals and their different taste sensitivities and eating habits. Dr. Reynolds has discovered a high incidence of super-tasters for PTC (bitter) among Barth syndrome individuals, but no super-tasters were found for sodium benzoate (salty).

Dr. John Jefferies (Cincinnati Children's Medical Center, OH) described in great detail what good pediatric cardiac care is and how different cardiomyopathies require different care plans. Dr. Jefferies emphasized that Barth syndrome individuals should be screened and have continuous monitoring for ECG changes, arrhythmias, and cardiac dysfunction to avoid bad outcomes, and that appropriate medical and device-based therapies should be provided for the appropriate patients.

Following the afternoon speakers, 25 posters were presented for discussion, which was the largest collection ever assembled specifically for Barth syndrome. The authors of four of the posters were selected to give oral presentations on the next day.

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Dr. Hilary Vernon



Dr. Jean Donadieu



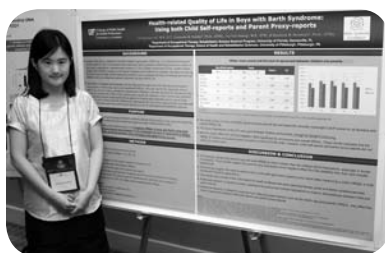
Dr. Todd Cade



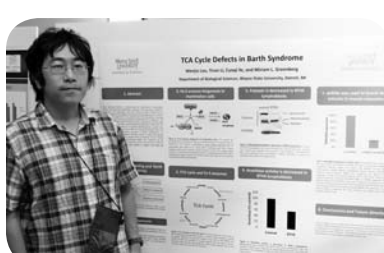
Dr. Stacey Reynolds



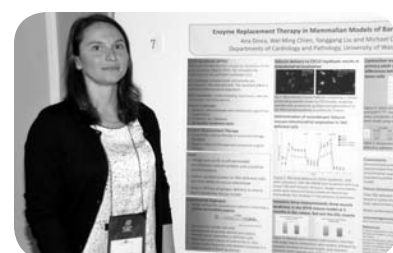
Dr. John Jefferies



Yoonjeong Lim, MS, OT



Wenjia Lou



Ana Dinca

2014 BSF Conference - The SciMed Sessions

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Friday, June 27, 2014

The morning session covered mitochondrial physiology. Dr. William Pu (Boston Children's Hospital, MA) presented his recent *Nature Medicine* article (also available as Open Access on BSF's website) using iPS cells differentiated into cardiomyocytes to clearly show the beating dysfunction of Barth syndrome and to analyze, in great detail, what is altered biochemically. This heart-on-a-chip technology has profound implications for basic and applied research beyond Barth syndrome. Dr. Junhwan Kim (Center for Resuscitation Science, PA) spoke about how the mouse model of Barth syndrome is helping us understand the real role cardiolipin plays in this disease, and Dr. Jan Dudek (University of Gottingen, Germany) spoke about how the oxidation enzymes are reorganized in Barth syndrome. The four poster authors selected to give oral presentations about their work were: Edgard Mejia (University of Manitoba, Canada); Ya-Wen Lu (Johns Hopkins University, MD); Michael Zaragoza (University of California at Irvine, CA); and Trisha Grevengoe (University of North Carolina at Chapel Hill, NC).



Dr. William Pu



Dr. Junhwan Kim



Dr. Jan Dudek



John presents the Varner Award to Dr. Gonzalez.

At noon, the Varner Award, presented to the pioneers of the science and medicine of Barth syndrome, was awarded to Iris Gonzalez, PhD of A. I. DuPont Hospital for Children in Wilmington, DE. Dr. Gonzalez has been an integral part of BSF and its international Scientific and Medical Advisory Board from the very beginning. Dr. Gonzalez personally records and annotates all the human *tafazzin* gene mutations—*tafazzin* is the gene that when mutated causes Barth syndrome. Dr. Gonzalez's insights into *tafazzin* gene structure and function contribute to our basic knowledge of this disease, but she never forgets that behind these mutations are real people suffering real problems. Dr. Gonzalez graciously remarked during her acceptance speech that the Varner Award was her Nobel Prize!

The afternoon session discussed animal models of Barth syndrome and specifically the work done in several laboratories with the *tafazzin* knockdown mouse model of Barth syndrome. Dr. Zaza Khuchua (Cincinnati Children's Medical Center, OH) and Dr. Colin Phoon (New York University, NY) described how the mouse model displays many of the same problems that Barth syndrome individuals experience. Of particular interest was the report about a potential knockout mouse model from Dr. Douglas Strathdee (Beatson Institute for Cancer Research, Glasgow, Scotland), and a report from Dr. Michael Chin (University of Washington, WA) using enzyme replacement therapy with the knockdown mouse model. Dr. Laura Cole (University of Manitoba, Canada) spoke about how fat is metabolized differently in the mouse model compared to normal mice making them "skinny", and Dr. Catherine Le (Buck Institute for Research on Aging, CA) discussed how mitochondria are defective in Coenzyme A metabolism in the mouse model.



Dr. Zaza Khuchua



Dr. Colin Phoon



Dr. Douglas Strathdee



Dr. Michael Chin



Dr. Laura Cole



Dr. Catherine Le

Survey feedback from the attendees was extremely positive—the best ever for these conferences. For 2016, we will continue to encourage young and new researchers to attend the conference, continue to showcase the therapeutic and potentially therapeutic activities that are taking place, and make more of an effort to attract physicians who may be caring for a single Barth syndrome individual. Videos of many of the speakers' presentations are available on BSF'S website for anyone to access and review.

The Barth Syndrome Foundation and Cardiolipin Research in Italy

(Cont'd from page 1)



Researchers and family members involved in the creation of Barth Syndrome Italy. (Photo courtesy of Dr. Angela Corcelli)

Dr. Toniolo knew of the Barth Syndrome Foundation (BSF) in the USA and thought that it would be nice to help the Italian families build a Family Association in Italy as well. She spoke to Dr. Donati and to Dr. Amelia Morrone, who had been doing the molecular diagnosis for the disorder, and together they decided to organize a meeting of Barth syndrome families. Five families participated in the first meeting that took place in Florence on December 6, 2012). It was a great meeting for everybody and for many was the first time they could meet and speak about their children and their difficulties. With no discussion, they all decided to fund a Family Association. A person from Telethon-Italy participated in the meeting to help with their expertise. Support also came from the American and the other European associations, and we are very grateful to all of them.

slowly moving to become a "real" organization, including becoming a BSF affiliate and hope to report further success soon. It has been difficult as we are few and we still have no funds. The President is Dr. Paola Cazzaniga, who started all this and two other parents (Margherita Usai and Carlo Benedetucci) are in the Directory. A website is planned and our main goal will be to use it to increase the knowledge of the disease and help with early diagnosis in Italy. We also plan to contribute to fundraising for research on Barth syndrome and to the other activities of BSF.

After more than one year, in February, the Italian Barth Family Association (BSI: Barth Syndrome Italy) was started. We are now

In parallel to the above events, researchers in the laboratory of Dr. Angela Corcelli at the University of Bari in southern Italy started to be involved in lipidomic studies of mitochondria and acquired expertise in cardiolipin detection. A novel method of analysis of mitochondrial lipids was developed (Angelini, et al JLR 2012), and in 2012, a grant to develop a diagnostic tool for Barth syndrome was awarded by BSF (Determination of the monolysocardiolipin/cardiolipin (MLCL/CL) ratio in intact nucleated cells: A new tool for the screening of Barth syndrome). Results, obtained in collaboration with Dr. Colin Steward and Ms. Ann Bowron of the NHS Barth Syndrome Service in England, were reported on at the 2014 BSF Conference in Florida; three Italian researchers attended the meeting thanks to the generous support of BSF. It was an extraordinary scientific experience especially in the context of the deep humanity of the BSF community.

Dr. Corcelli has also established contacts with the Meyer Hospital in Florence and organized seminars and talks on Barth syndrome in Bari. In September 2013, thanks to the invaluable support of Dr. Michael Schlame, she organized the first international cardiolipin workshop (<http://onlinelibrary.wiley.com/doi/10.1002/ejlt.201300385/abstract>). Dr. Cazzaniga attended the meeting and met Dr. Schlame and other scientists involved in cardiolipin research with the goal of finding therapeutic solutions for Barth syndrome. Next year, in September 2015, a second Cardiolipin Meeting will be held in Florence. It is going to be very informal, but we hope that all of the scientific community interested in elucidating the role of cardiolipin in Barth syndrome (the so-called "cardiolipin gang") will participate.



Dr. Daniela Toniolo & Shelley Bowen at BSF's 2010 Conference.



Florence Mannes, Sue Wilkins & Dr. Daniela Toniolo at BSF's 2010 Conference.

Reflections from my First Barth Syndrome Conference

By Brittany DeCroes, PT, DPT, Kennedy Krieger Institute, Baltimore, MD

"... The Barth Syndrome Conference was truly unlike any conference that I have previously attended. Every person that I met there was extremely hospitable and supportive. It is such a sincere and close knit community and I look forward to the opportunity to attend future conferences so that I can work with the foundation, the families, research participants and the clinicians to continue to improve the lives of those diagnosed with Barth syndrome."

Brittany Decroes, PT, DPT

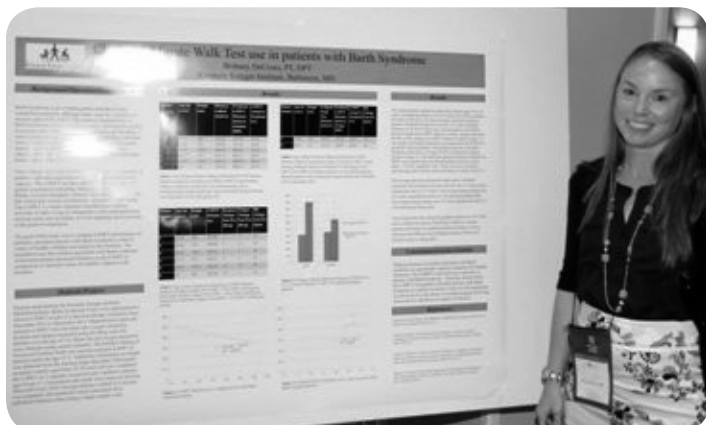
I had the pleasure of attending my first Barth Syndrome Conference this past June. At the Conference, I had the opportunity to present a poster regarding "Clinical 6-Minute Walk Test Use in Patients with Barth Syndrome," and participate in a research project with members from the Kennedy Krieger Institute Barth Syndrome Clinic. For the research, I was able to administer the 6-Minute Walk Test (6 MWT) and assess lower extremity muscle strength via hand-held dynamometry and manual muscle testing. Prior to attending the Conference, I felt that this work was important to those diagnosed with Barth syndrome for several reasons:

1. To provide an objective measure of the functional ability of those with Barth syndrome in addition to the research participants' and families' descriptions of their functional activity;
2. To provide a pre- and post-level of functional ability following undergoing an intervention (such as a medication or an exercise program) to provide quantitative data on gains made; and,
3. To determine if there is a difference between the functional abilities of the boys and men affected and determine why that might be occurring.

While presenting the poster and participating in the research project were great, I found the most rewarding part of the Conference was the direct feedback that I was able to receive from the research participants and their families regarding the potential benefits my research can have for them. One mother provided feedback that she felt that the use of the 6-Minute Walk Test would further assist her with advocating for therapy services for her child in school, which was something that she was currently struggling with.

One of the preliminary findings of my research is that the men with Barth syndrome walk approximately 46% of the predicted 6 MWT distance while the boys ambulated approximately 70% of the predicted 6 MWT distance. Upon seeing this information, one man with Barth syndrome stated he feels it is a lot more difficult for him to do things now than when he was younger and is hoping that my research can help determine why that is.

A clinician provided great feedback regarding determining if there was a correlation between 6 MWT distance and VO₂max in those diagnosed with Barth syndrome. If a correlation was documented, this could result in increased 6 MWT use in practice and research and spare the boys and men from participating in rigorous VO₂max testing, which is very challenging for them.



Brittany DeCroes presents her poster at BSF's 2014 Conference.
(Photo courtesy of BSF)

The feedback I received from the boys and men diagnosed with Barth syndrome while performing the research was extremely inspiring. One man, who agreed to participate in the research project despite having to patiently wait for me while I was running approximately 45 minutes late, stated "It's not a problem, I want to do anything I can to help the boys."

The Barth Syndrome Conference was truly unlike any conference that I have previously attended. Every person I met there was extremely hospitable and supportive. It is such a sincere and close-knit community, and I look forward to the opportunity to attend future conferences so that I can work with the foundation, the families, research participants and the clinicians to continue to improve the lives of those diagnosed with Barth syndrome.

Barth Syndrome: A New Perspective—A Successful Culture

By Valerie "Shelley" Bowen, Director, Family Services & Awareness, Barth Syndrome Foundation



Shelley Bowen

How do you define the success of a non-profit organization such as BSF? Sometimes it's not so easy to sum that up in a neat little graph. Numbers are important because you can objectively measure our growth, but the culture of who we are is equally important as those tidy charts. Just prior to the last newsletter, we released a series of interviews, which included perspectives from families, researchers and clinicians in this group. The common thread throughout each of these interviews was an observation that the very culture of BSF was what sets us apart from others. Each person described that culture a little differently. In 2007, we set out to describe that culture through our value statements, which are outlined in the "About BSF" section of our website. These value statements are more than idle words. They are the defining characteristics of the culture of our community.

In some ways, finding people who have been diagnosed with Barth syndrome or insuring they receive an accurate diagnosis could be likened to giving birth. It is just the beginning of a long nurturing relationship. This nurturing, concern and compassion, that extends throughout our community sustains our relationships with families long after they press the send button in search of answers. When they come to us they have finally found a sense of place.

Our community is evolving, but that sense of place still exists. We are expanding our efforts to serve the special needs of our carrier community, Barth syndrome individuals who have received transplants, and men who have Barth syndrome. In some ways, our need to better serve the men in this community could be considered a success in itself because at one time parents were given little hope for their sons to live beyond infancy. Now, some are moving away from home to attend school and having families of their own.

We are so very thankful for the volunteers and donors who give us the resources we need to continue to be an organization that makes a difference. I once knew many of these volunteers when they came to us as children or when they were struggling to understand what was going on with their son. They have become a formidable force of proactive advocates engaged in propelling our mission. Now that's success.

BSF Programs Are Expanding To Meet Special Needs

By Rebecca McClellan, MGC, Kennedy Krieger Institute, Baltimore, MD and Lee Kugelmann, Volunteer, Barth Syndrome Foundation

This summer saw the launch of a new program under the Barth Syndrome Foundation's (BSF) Family Services umbrella, the Carrier Services Program, dedicated to meeting the needs of our carrier women through support and education. At BSF's 2014 Conference, we held sessions with women of all ages to discuss the impact carrying the gene for Barth syndrome (BTHS) has had on their lives. These conversations were incredibly moving, and the honesty and enthusiasm with which they were held speaks to the importance of this program. Women spoke of guilt, feeling isolated and judged, and the impact this has had on their relationships and life choices. Some such stories are featured below. We also heard a message of great hope for the future, and we are working to continue this conversation through programming and continued education about carrier issues.

By Susan Hone, Mother to Jess, Jen, Jordan (BTHS deceased), Josh and Jared (BTHS)

Each person's reaction to being a carrier of Barth syndrome is different. My reaction is guilt. I have two adult daughters, one is a carrier. I feel guilt that they had to be tested, guilt in the results, guilt in having to tell her future husband her carrier status, guilt in the decisions they had to make to have a family, and guilt that my beautiful granddaughters are one day going to have to go through this same cycle.

I did not know I was a carrier until after I had all five of my children. I knew nobody who had been through what I had. Carriers today have many options and resources that were not available to me. The ability to share experiences with others is invaluable and the establishment of a carrier issues group is a welcome addition to the support BSF provides.

By Nicole, Mom of Affected Individual, Michigan

My original interest in heart transplantation began the moment I was told my infant son would never leave the hospital without it. Devin received his donor heart 10 years ago, and the diagnosis of Barth syndrome eight years ago. Since that time, my interest has evolved to focus on heart transplantation in the Barth syndrome (BTHS) patient, about which there appears to be very little research. I, along with Stephanie Rader and Shelley Bowen, have set out to change this and convince all affected by Barth syndrome why a greater emphasis should be put on this topic. The sobering fact is that every male diagnosed with Barth syndrome may one day be faced with being listed for transplant; we need to embrace this fact and find a way to make everyone more comfortable with this subject. We reached out to those most knowledgeable on the subject: BSF families that have first-hand experience with heart transplantation.

BSF Gives Us Hope For Our Future

By Patrice Whitby-Allen, Fiancée of Affected Individual, Philadelphia



Darryl (age 32) and Patrice.
(Photo courtesy of Patrice 2014)

Two years ago, a friend of mine from high school invited me to his church. He had become the Pastor of the church a few years before and had been telling me I should come for a visit. A few weeks later, I decided to go visit his church. I remember it was the first Sunday in January, right after the New Year. My motto at the time was New Year, New Beginnings! Little did I know I was about to meet my fiancé, Darryl.

Darryl and I seemed to have a connection from the beginning. I met him in church. He was the guy who was always running around helping the Pastor or members of the congregation. You couldn't help but notice him. When I first encountered Darryl, he seemed to be quiet and shy. He was friendly but a little reserved. However, I was drawn to him.

Over time, as we got to know each other, I think my bubbly personality was able to break through, and soon we became friends. Come to find out, we had a lot in common. The biggest thing was the work we were doing for the church and how involved we were in the ministry. Darryl and I would talk on the phone for hours. We would laugh together and cry together. He became my best friend. It was a few months into our friendship that he told me he had a heart condition and sometimes doesn't feel well, but that's all he said.

It wasn't until our friendship matured that he told me he had Barth syndrome. I remember searching Barth syndrome on the internet to learn more about it. I loved Darryl, so I wanted to know everything there was to know about him. There were times when he didn't feel well, but he never made a big deal about it. Since I had done my research on Barth syndrome, I was aware of why he didn't feel well, but rarely did he ever acknowledge it was Barth-related.

Our friendship evolved into the romantic relationship we share now. When Darryl proposed to me, it was one of the happiest moments in my life. I was totally surprised and excited because I was blessed with the opportunity to marry my best friend. One of the things I love most about Darryl is that Barth syndrome doesn't define the man he is. He lives with and advocates for Barth syndrome, but he doesn't let Barth be the end of his story. That's one of the things I love most about him. Barth syndrome is what makes Darryl special. It's what makes him stronger, more eager, genuine and also compassionate. Those are some of the qualities that I wanted in my ideal soul mate. I thank God because he sent me Darryl.



Darryl and Patrice at BSF's 2014 Conference.



Darryl and Patrice enjoy a stroll on the beach.
(Photos courtesy of BSF 2014)

BSF Gives Us Hope For Our Future

By Morgan, Wife of Affected Individual, Michigan



Morgan and Joshua (age 31).
(Photo courtesy of Morgan 2014)

Josh and I have been together for about five years and, married for three. We met in Cape Coral, FL. Ever since we've been together, I've known that he had something physically wrong with him, but neither of us knew what it was. I remember him telling me one time that he could literally die any day because of a severe heart condition he had since birth, but I remember noticing other strange things. Anytime Josh would get sick, it would take him much longer to get better than anyone else I'd ever met. He always seemed to be tired, and he didn't eat much. People in my family and friends of mine used to tell me that they thought he was just lazy, that he didn't look like there was anything wrong. They had a hard time believing that someone who looked so normal was so sick. Then his health started to get worse.

The first time Josh went into the hospital in Florida was for heart palpitations. I remember being so scared when he called me and told me what was going on. He had let it go for several days before deciding to tell me. I had known that he was not feeling well when I had seen him last, but I didn't realize how serious things were. Josh was in the hospital for about a week before his heart went back into normal rhythm on its own.

Within the next year, Josh's heart troubles continued to get worse and worse. He was constantly in the hospital, sometimes for a week at a time, and the doctors were unable to give us any answers. He became sick more frequently, too, and would get sores and infections that would also require hospitalization. Soon, he was unable to work because of how often he was sick and his heart was going out of rhythm. Josh and I decided it would be best if he moved up to Michigan to be with his family because we weren't sure of how much time he had left.

When we got up to Michigan, Josh decided to see the pediatric cardiologist who had taken care of him and his brother. The doctor never told us anything other than recommending that Josh see an adult cardiologist, but when we got home I noticed the diagnosis of Barth syndrome written on a prescription note. Josh didn't know anything about it, so we decided to look it up and came into contact with Shelley Bowen and the Barth Syndrome Foundation.

Finding a name for this mystery disease that was slowly killing the man that I loved and knowing that there were possible treatments was overwhelming. When we attended BSF's Conference, I was absolutely blown away. There were other men Josh's age who understood what he was going through. I've never seen him so lit up as he was around his Barth brothers. It was absolutely incredible to see him so optimistic about his future.



Joshua introduces himself and Morgan at the Welcome Ceremony at BSF's 2014 Conference. (Photo courtesy of BSF 2014)

Since leaving the Conference with the advice we were given and everything we had learned, Josh's health has improved quite a bit! I've seen him do more than he even thought he was capable of (lifting things that he never would have been able to handle on his own, putting together furniture, exercising).

The Barth Syndrome Foundation has given us hope for our future—something we weren't sure we would have. Instead of talking about what will happen when he passes, Josh now talks about our family, things he wants us to do together and the life he wants us to build. Instead of being afraid of what might happen, I'm excited!

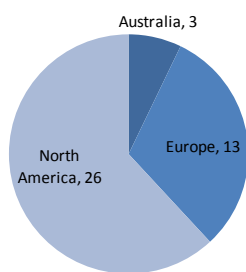
The New Barth Syndrome Registry (BRR 2.0)

By Valerie "Shelley" Bowen, Director, Family Services & Awareness and Matthew J. Toth, PhD, Science Director, Barth Syndrome Foundation

In 2012, the Barth Syndrome Foundation (BSF) was one of 31 agencies selected by the National Institutes of Health (NIH) to participate in the Global Rare Disease Registry (GRDR), a web-based resource for rare diseases. This resource would aggregate, secure and store de-identified patient information in one place so that data about common symptoms that are shared by numerous rare diseases could be compared across those rare disease's registries. Through this initiative, common data elements (CDE) were established so that there will be some commonality across numerous registries and national databases. The goal of both the GRDR and the BSF as a participant is to make data more broadly available to scientists who can use this information to conduct analysis across many diseases and increase research interest of Barth syndrome.

Historically, research participants were uniquely de-identified through institution specific standards thereby resulting in one person having numerous different references (i.e. FAM 3, #5, PT 204, etc.) in various journals that couldn't be connected. Now, though, participant data is associated with a Global Unique Identifier (GUID) which will track the participant over time and across research studies. This approach will protect the participant's privacy but also enable a participant's clinical data to be linked with his/her biological specimens.

Some symptom-specific questions that were not among the CDEs but that are important Barth syndrome itself were included in the new Barth Syndrome Registry (BRR 2.0). When available, we used questions that had already been developed by groups that perform this work, such as PhenX and PROMIS. When questions were not available through these agencies, we benchmarked other well-recognized and established groups and used common questions and responses from their registries, such as the Severe Chronic Neutropenia International Registry (SCNIR). Our BRR 2.0 approach differs significantly from that of the Barth Syndrome Registry and Repository (BRR 1.0) in which data was abstracted by a registry coordinator to populate data sets in various disease specific domains. Now, the participant or the participant's guardian enters the information directly into the registry.



Registry participants

On August 18th, 2014, we opened enrollment into the BRR 2.0. Presently, 42 individuals have signed up for this new BRR. The data that is entered is housed on a secure server and supported by a company called Patient Crossroads. There are a total of 103 questions spanning seventeen specific domains (i.e., cardiovascular, endocrine, gastrointestinal, etc.). In addition, participants may provide names and contact information of healthcare providers who want to receive updates about the registry. Measurement data (height and weight) spanning the life of each participant is also requested. Furthermore, participants are asked to provide documentation that would confirm a diagnosis of Barth syndrome which is used to authenticate the data being associated with the individual. Fifteen of the 42 participants have submitted such documentation. Twelve registry questionnaires have been completed and verified. Additional information has been requested from 24 participants. Fortunately, participants have been responsive to these requests. It is our goal to have 100 verified participants enrolled in the registry by the time you receive an update in our next newsletter.

For more information about the BRR 2.0 visit our website at www.barthsyndromeregistry.org.

Save the Date!

Barth Syndrome 8th International Scientific, Medical & Family Conference

July 18—23, 2016
Hilton Clearwater Beach Resort
Clearwater, FL



Thanks to the Bakers, the Bikers, the Bowlers, the Walkers, and Those who Chop, Putt, or Just Get Together to Raise Money!

By Sandra Stevens, Fundraising Project Manager, Barth Syndrome Foundation



Sandra Stevens
at BSF's 2014 Conference.

Your donations are precious to us, and without your contribution we really couldn't do what we do. These include the ground-breaking research, support for families, not to mention our unique and highly-regarded conference. None of these programs could happen without your help. We are grateful to all those who respond willingly to our request for donations and are helping us get a little closer to our ultimate vision of a world in which Barth syndrome no longer causes suffering or loss of life.

I had the joyous pleasure of meeting a number of the boys and their families at the Conference. There was a lot of laughter, much splashing in the pool, and some amazing superhero costumes at the party. There was also a lot of very valuable work done in the clinics and sessions. The consultations attended by those boys and men is essential in continuing the good work that's already been done. I saw donor dollars in action, making a very immediate difference to those who attended, and a lasting one to all affected families. Your donations are changing lives.

As we move into the close of 2014, we ask that you help us reach our fundraising goal of \$1,000,000. If you haven't already made your contribution, and even if you have, please consider helping us reach this target.



'Tis the season for **#GivingTuesday**. On December 2, on the heels of Black Friday, Small Business Saturday and Cyber Monday, this day is dedicated to giving back. We'll use social media to invite everyone in the Barth Syndrome Foundation (BSF) community to spread the word and raise awareness of Barth syndrome, as well as launch the season of goodwill by asking for a donation. Last year we raised nearly \$10,000 in ONE DAY. Let's see if we can beat that in 2014!

In the spirit of giving thanks, this year as many before, some of our supporters showed that they were prepared to go to extreme lengths to raise money for BSF. Some more painful than others! We owe these motivated people a huge thank you.



Bryan, along with family and friends, play bingo for Barth!

Bingo for Barth

Bingo for Barth syndrome in February was a great start to the year, thanks to the organizational skills of Bryan in Overland Park, Kansas, and his friends' luck with the numbers. This is a fun, sociable way to get people involved in raising money and awareness, particularly if you can get some donated prizes to make it more interesting. Eyes down!

Happy Heart Walk

Early in 2014, we welcomed Megan, John and their family to BSF. They immediately arranged to hold a walk in February to raise awareness and donations. In the end, nearly 200 people attended. Local businesses in California's Bay Area, contributed goods and money, including the catering. Also, Megan and John sold T-shirts, which are now being worn as far as Texas, Oklahoma, and Arkansas. The event was hugely successful, but even a simple picnic can be a way to raise funds. Maybe there's a caterer or store you can ask to donate the food and drink. (Read Megan's article on pg. 17).



Megan, John, along with family and friends, walk for Barth!

(Cont'd on page 14)

Thanks to the Bakers, the Bikers, the Bowlers, the Walkers, and Those who Chop, Putt, or Just Get Together to Raise Money!

(Cont'd from page 13)



Young volunteers at the Community Yard Sale!



Michael Neece breaks boards for Barth!



Jocey Buly and friends ride for Barth!



Gary and Julia Rodbell @ Timberman Ironman.

Chick-fil-A Fundraiser

On the subject of food, in May, a young student in Greensburg, Pennsylvania was asked to organize a fundraiser as a school project. She chose BSF as her beneficiary, and held an event at Chick-fil-A, where she invited friends and family to dine and donate. Many restaurant chains offer to host such fundraisers. Some even help with the design of flyers. The best part is that they do all the cooking and dish-washing! You just ask your friends to turn up on a given day and buy dinner as normal.

Bake Sale

And for dessert? Elizabeth Davis is in Perry, Florida and is a very good friend of BSF. She decided to help raise money for the 2014 Conference by raffling cakes and gift cards. Any cakes remaining after the raffle were sold to raise additional funds. Do you know any enthusiastic bakers or candy makers who'd love a chance to show off their flair?

Conference 2014 Individual Appeals

And talking of the Conference, in addition to the money raised for this year's meeting by a written appeal in May from BSF, several families sent their own donor appeals to their communities. These were based on the wonderful "Henry Cards", designed by Tiffini Allen. Thanks to all those families who helped to raise money for the Conference amongst your family and friends. If anyone wants to create a similar card to raise money, we can help. All you'd need to do is print and mail it.

Community Yard Sale

Our own Executive Director, Lindsay Groff, held her third annual yard sale. She joined forces with other homes in her community to host the sale, with a portion of the proceeds going to BSF. Yard sales offer a great way to raise money as it takes minimum organization and you can get rid of those things you no longer need, all while helping BSF.

Breaking Barth

Michael Neece is a keen taekwondo expert and a valued friend of BSF. He succeeded in breaking 500 boards one Sunday afternoon in July, using both feet and one hand, to raise money for BSF. Early in his training he broke his other hand, but he never considered cancelling. His local Lowes Home Improvement donated some of the boards, and his taekwondo club hosted the event. Is there a sport or activity you love, where you can invite an audience and raise money, ideally without breaking any bones?

RideLondon 100 Mile Bike Ride

In August, Jocey Buly, a dear friend of one of our families and the daughter of two of our valued US donors, took part with her boyfriend in a major 100 mile bike ride through London and the surrounding countryside, to raise money for Barth Syndrome Foundation and Barth Syndrome Trust. They had to battle the remnants of Hurricane Bertha, which made their effort all the more gallant. Jocey's parents emailed their friends here in the US to raise donations and matched them with a \$10,000 donation of their own! Did you know that matching donations often inspire people to give more?

(Cont'd on page 15)



Devin and friends celebrate his 10th birthday!



Team Will members at the Jarden Westchester Triathlon.



Stefan proudly crosses the finish line at the Hawaiian Ironman Triathlon.



Bowling for Barth is in its 11th year!

Timberman Ironman

We've become quite familiar over the years with Team Will and all the amazing work they've done to raise awareness and money for BSF, competing in triathlons and similar events. Julia Rodbell is the daughter of Gary, the founder of Team Will, and she has picked up the baton for the next generation and completed her first Ironman event in August for BSF. But by barely breaking a sweat, even a 5k walkathon can make a difference, and BSF staff can help promote the event and let people know how to donate.

Devin's League of Superheroes

It was Devin's 10th birthday recently and the 10th anniversary of his Gift of Life donor heart, so his parents created a mini-golf day fundraiser for which they sold tickets. The day was a great success, despite less than perfect weather. They were blessed by the presence of the (heart) donor family who came along with around 20 of their own friends to support the event. Altogether, around 100 people attended. Mini-golf is fun for any skill level or age-group and guaranteed to attract an enthusiastic crowd.

Jarden Westchester Triathlon

For 11 years now, this event has been a popular one for Team Will. This year, team members took part in this "sprint" triathlon event in September. Despite such a misleading classification, it's still a 0.9-mile swim, a 25-mile bike ride, and a 6.2-mile run! That's more than most of us would plan for any Sunday morning, but for Gary Rodbell, who was celebrating his birthday on that day, he chose that over breakfast in bed as a treat!

Hawaiian Ironman Triathlon

There's no dismissive "sprint" or "lite" qualification applied to this event. Stefan Tunguz, who usually participates with Team Will, was one of very few people to win a place at the toughest Ironman of them all in Kona, Hawaii. He swam 2.4 miles, biked a further 112 miles, then ran a full 26.2 mile marathon. He finished all this in an amazing time of 15 hours and 18 minutes. All this while wearing the Team Will shirt, to raise awareness and funds for BSF.

11th Annual Bowling Fundraiser

This much-anticipated fixture is now firmly in the calendars of John, Liz, Jack, Kelsey and Olivia, plus their family and friends. I'm sure they will have spent the whole year honing their bowling skills, or maybe it's more fun if they haven't! Did Warwick, NY resonate with the cheers of success or groans of frustration? When they're raising awareness and dollars for Barth syndrome, I don't suppose it matters either way to them.

S.W.O.R.D. 2nd Annual Blades Battling Barth

In September, SWORD and NKY Fencing Academy (NKFA) partnered together again for the premier Midwest fencing event: 2nd Annual Blades Battling Barth Syndrome Open! Many fencers, stabbing, parrying, thrusting and slashing away with Saber, Foil and Epee for hours. Thanks to Brie and Ned for turning another passion into a great way to raise funds.

Spike it on Barth Syndrome

In November, Bryan will add to the Bingo for Barth success and is sure to have recruited some keen sports-people with a good spring in their stride, to take part in an indoor reverse co-ed 4's volleyball tournament. Teams or individuals pay to play, or just donate anyway. Another great example of someone doing what they love and raising awareness and donations at the same time.

Thanks to the Bakers, the Bikers, the Bowlers, the Walkers, and Those who Chop, Putt, or Just Get Together to Raise Money!

(Cont'd from page 15)

Veterans Day 10K & Walk

Eleanor Fanto is a close friend of the McCurdys and in a wonderful gesture she entered this 10K in the nation's Capital, in support of Team Will and BSF. The stunning course along the Potomac River takes in the FDR and Jefferson Memorials, circling the Tidal Basin, and finishing in West Potomac Park. What a noble way to honor all our beloved fallen heroes.

2014 Conference Revenue

The total revenue for this year's Conference, including grants from the National Institutes of Health, totaled \$90,289, the most ever raised for a conference. More than two-thirds of that was contributed by individual donors. Those donations came from the appeal letters mailed in the spring, sponsorships, and onsite fundraising activities like the silent auction.



S.W.O.R.D 2nd Annual Blades Battle for Barth.



Abram (age 7) and Bryan will spike it on Barth!



Eleanor Fanto and Eliza McCurdy.

Financial Advantages To Donating Appreciated Stock

Have you enjoyed a little success in the stock market? Here's something you might not know. If you donate appreciated stock instead of cash, you can take an immediate tax deduction for the full market value of the stock and also avoid the capital-gains tax you'd owe by cashing in the securities. Then, using the cash you might have otherwise donated, you can repurchase the same stock at a higher cost basis for capital-gains purposes. Basically, there are financial advantages to donating appreciated stock instead of cash.

If you'd like to talk more about the ideas featured, or any other ways to raise money for BSF, please contact me, Sandra Stevens, at sandra.stevens@barthsyndrome.org, I'll be happy to call you to discuss your idea, and support you in getting the word out. Planning an event? We can feature it on BSF's website, with its own unique link. That way you can direct your friends and family to a straightforward way to support your event and BSF, online. I can help with any emails, letters and press-releases you may want to create.

You Can Make A Difference

Donate by check: Make check payable to **Barth Syndrome Foundation, PO Box 582, Gretna, NE 68028**

Donate online: You can donate to BSF by going to our website, www.barthsyndrome.org, and clicking on the "DONATE NOW" link on our home page.

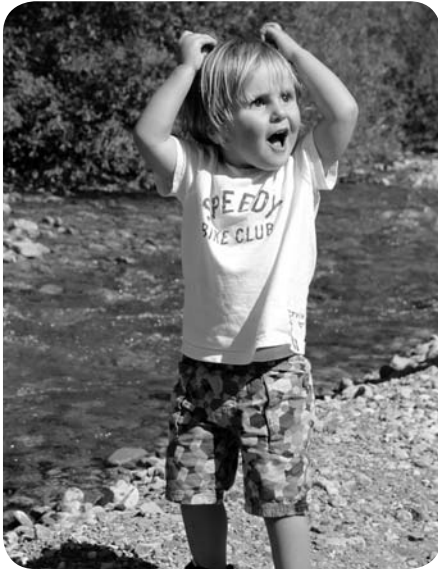
Employer Matching Gift Programs: Many donors are now taking advantage of a "Matching Gift Program" offered by their employer. The employer matches the funds donated by the employee to a charity and provides a convenient method for the employee to donate to a charity of his/her choice.

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.



Annual Happy Heart Walk

By Megan, Parent of Affected Individual, California



The Happy Heart Walk started in 2013 on behalf of my son, Henry, who is a delightful, happy and sweet 2½ year old. At three months of age, after not growing very much at all and a series of tests, he was admitted to Children's Hospital Oakland. Within 24 hours of being admitted, he had a confirmed diagnosis of severe dilated cardiomyopathy, meaning that the left ventricle of his heart was extremely enlarged, causing his heart to not function properly. We spent the next five weeks in the Pediatric ICU trying to get Henry's heart function stable and strong enough to come off of his intravenous medications and on to oral ones so that we could bring him back home. After five weeks as an inpatient, Henry was able to come home and we have been trying to have as "normal" a life as possible. It was just before Henry's first birthday that we received results back from genetic testing revealing why Henry had dilated cardiomyopathy and why it hadn't healed...Barth syndrome.

We are very thankful for the timing of how everything happened, knowing now that Henry was extremely close to being a very, very sick baby; thankful for watchful and proactive doctors who sensed something wasn't right; thankful for stabilizing medications and thankful for perfect timing and protection that we feel very fortunate to have received. We were at first terrified of his diagnosis of Barth syndrome, but we are now so thankful to know it. There is power in knowledge, and with the diagnosis came the power to know more and treat accordingly.

Henry's heart function remained stable with a low ejection fraction for just over one year, until it slowly started functioning better, and now his ejection fraction is just above the normal range! Henry is now a good eater, taking everything orally, which is such a relief after having been on an NG tube until he was 20 months old. He is working on getting caught up with his peers in hitting milestones by receiving 3-4 hours of various therapies per week for the past year and a half. He has the most wonderful big brother, Grady, who is constantly teaching him, loving him, praying for him, and wrestling him.

The past 2½ years have been quite a journey, definitely the most trying time in our lives, but also a time of feeling very loved and supported by our family, friends, and Barth syndrome community. Without this support group, I'm not sure how our family would be surviving! Community is very important to us, as is Henry, so putting together some kind of event bringing these two together weighed heavy on my heart.

In February 2013, prior to Henry's Barth diagnosis, when we were in the thralls of dealing with Henry not being well and trying to figure out life, we hosted the 1st Annual Happy Heart Walk for our extended family and close friends. The purpose was to honor Henry and to promote awareness of pediatric cardiomyopathy. It was sweet and simple, mostly because that was all I had the capacity for, but it ended up being great!

This year, February 2014, we did the same, but bigger and better, getting our local businesses involved and making it a fundraiser. All funds were to support the Barth Syndrome Foundation (BSF) and the good work and research they are doing to help find a cure for Henry and all the boys/men currently suffering and the ones to come. The Foundation has been extremely helpful to us since Henry's diagnosis. And since Barth syndrome is so rare, we feel that it is even more important that we do all that we can do to help the Foundation. With the generosity of our community, friends, and family, we collectively raised over \$10,000, not to mention a lot of awareness of what Barth syndrome is! Not only did we raise a lot more money than I had anticipated, but we had a really special day surrounded by people who love us and people who care in our community.

With the success of the 2nd Annual Happy Heart Walk and after attending the BSF Conference this summer, our desire to continue hosting this fundraiser is even stronger than before. We have been blown away by the transparency and sincerity of the people involved with BSF and truly inspired by meeting the boys and young men affected by Barth syndrome. Every day we live and breathe the reality of what this disease means, and if we can do anything to make it better, we will try.

.....
The Happy Heart Walk received its name from a Bible verse that a dear friend sent me when Henry was first diagnosed: "A happy heart makes the face cheerful..." Proverbs 15:13

What this has meant to us is that even though Henry's heart has been "sick", it has still been happy. And that has always shown on his face, through all that he has been through. His health (and circumstance) has not determined his happiness, and that is what we strive to implement in our own lives each day.

In Loving Memory of Will McCurdy

By Valerie "Shelley" Bowen, Director, Family Services & Awareness, Barth Syndrome Foundation



Michael Bowen, Will McCurdy and John Wilkins at BSF's first family gathering in 2000 in Baltimore, MD.

There was once a golden haired young boy who dreamed of nothing more than to meet someone who was just like him, another boy with Barth syndrome. He was deeply loved by his parents who had attempted with all their might to find these boys. You see, his parents' desire to find other boys wasn't simply about fulfilling their son's wish. His life was in danger. His parents scouted every lead they could find which always ended the same, "There are no boys here." But, the boy and his parents never gave up hope. One beautiful spring day, the boy's tenacity paid off. His cry of joy echoed through the house when he discovered three mothers who were conducting a search far and wide for other families just like his.

The boy was very determined that it should be he who should respond. After all, it was he who found the information. So, with his parents blessing, the boy responded, "I'm here!" Within minutes, the mothers responded with news proclaiming a great gathering of boys and their families from around the world that would take place in Charm City. Weeks later, the boy and his parents made a perilous journey to reach

Charm City. When they arrived, the boy bolted in the door, barely able to contain his excitement. There before him were boys just like him. There before his parents were other parents just like his who were there to change the future for their children. This small boy's determination to find others was the catalyst of change for all those who have Barth syndrome.

I was one of the mothers who received that first introduction to the McCurdy family, which came from Will. Other than my own two children, Will was the first child with whom I had ever had been directly in contact with who had Barth syndrome. It was clear from the very beginning that Will was extraordinary.

Had it not been for Will's determination to get to Baltimore (aka Charm City), I seriously doubt there would be a Barth Syndrome Foundation today. It has been fifteen years since I received that first message from Will. Since then, he has inspired me to be kinder than I thought I could be by his example of thoughtful and selfless expression. He has been quietly heroic.

I am blessed to have so very many fond memories of Will. But, oddly enough, it was that first image of the thin silhouette of a boy in a red plaid shirt and khaki pants who stood in the doorway as he introduced himself and family with his mother's loving hands resting on his shoulders, that I recalled when Kate told me our precious Will was gone. I ache at the very thought of a world without Will McCurdy. In what would be our last conversation, Will spoke of all the boys he has come to know and love over the years. He spoke of them with such fondness. His last words to me were "I love you, Shelley. Never give up." I promised him I wouldn't, and that is a promise I intend to keep. Goodnight, sweet prince.



Dr. Barth and Barth boys/young men at BSF's first Family Meeting in 2000.



Kate, Eliza, Will and Steve touring Manhattan.

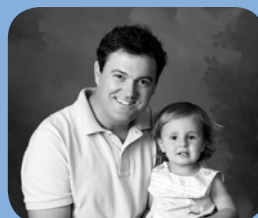
Awareness of Barth Syndrome Continues to Grow

There has been a significant increase in Barth syndrome (BTHS) related peer-reviewed journal articles published. To date, a total of **81** articles have been published on BTHS research conducted with the support of BSF and/or BSF affiliate funding (denoted below with *) and publications that acknowledge biological samples and/or information from Barth families, the Barth Syndrome Registry and Repository, and/or BSF affiliates (denoted below with Δ). 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 BTHS, please visit www.barthsyndrome.org.

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Luke (age 2) & Emily



John & Henry (age 2)



Levi & Amy (age 2)



Tracy & Brayden (age 4)



William (age 10)

Awareness of Barth Syndrome Continues to Grow

(Cont'd from page 19)

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Cecilia & Mario (age 11)



Noah (age 12) & Carol



Sam (age 14) & George



William (age 15)



R.J. (age 16) & Lee

Our Latest News from Barth Syndrome Trust

By Michaela Damin, Chair, Barth Syndrome Trust



Having fun at the Family Day. (Photo courtesy of Alex Smith 2014)

The Damin family, along with eight other UK families, gathered at the Bristol Royal Hospital for Children in September this year for two days of clinics and talks, with individual as well as group sessions across the spectrum of cardiology, haematology, occupational therapy, physiotherapy, speech and language therapy, dentistry and dietetic management. As with any group gathering of Barth families, this clinic also provided a time and place for informal discussions as well as some heartfelt and emotional exchanges amongst families, all of which make dealing with the realities of Barth syndrome just a little easier to bear. It is very special watching how the children and young people are so excited about meeting up again and just fall back naturally into their easy-going friendships.

After lunch we all gathered in the Playroom to watch Dani create her stage magic with her new puppet show especially designed to explain Barth syndrome to young children. Being able to educate schools in this age-appropriate manner will dispel many of the myths or ignorance surrounding Barth syndrome and will make school life easier for our next generation of children entering school. See her article on page 22 for more information.

The NHS team also explained about their new 24-hour tapes or holter monitors which will be available for boys and men who might be experiencing rhythm problems. This easy-to-use continuous ECG can be delivered to families' homes. Following clear instructions you can place the electrodes in the correct place and start quickly. Once finished, the device can simply be posted back in a secure fashion for analysis at the hospital. Since many of our families live far away from Bristol, we welcome these kinds of advances that mean that the lives of our boys and men are disrupted as little as possible, whilst still providing a high standard of care.

Other news included the promotion of Patients Know Best (PKB), a secure patient-held online medical record. PKB was ranked as the leading Personal Health Record in a study commissioned by the UK government. The authors ranked records from around the world on a four point scale. PKB was the only one to reach level four. Using PKB means that I can have all of my son's medical records, lab work and clinic letters easily accessible wherever I am in the world, and I can contact members of his team securely with any questions or concerns. At the moment, I am compiling my son's records so that I can hand these over to him when he is ready to take over his own health care. Without this I can safely say he wouldn't have a clue about much of his medical history, especially from when he was much younger.

The bezafibrate clinical trial is due to go ahead with an anticipated start date in spring next year, and families are very excited at the prospect of being able to participate in this important project.

The ever popular Family Day after the Clinic was held at Noah's Ark Zoo Farm with over 40 people attending. There were so many animals to see, great interactive talks, plenty of play areas and pizza for lunch! A good day for all.

We wish everyone the best of health as winter approaches here and look forward to seeing you at the next Clinic and Family Day in May 2015.

**Next NHS Barth Syndrome Service Clinic
14—15th May 2015**

Family Day on Saturday 16th May 2015

Tommy and Jasmine are Behind You!

By Dani Goodman, Paediatric Occupational Therapist, Bristol Royal Hospital for Children, Bristol, United Kingdom

The NHS Barth Syndrome Service based at Bristol Children's Hospital in the UK has introduced two new members to their team. Tommy and Jasmine are two lovable puppets who will be visiting a number of pre-schools and primary schools accompanied by Dani Goodman, Occupational Therapist for the Barth Syndrome Service.



Tommy and Jasmine

Dani has created these puppets to help our younger boys to have a better understanding of Barth syndrome and also feel more confident in talking about their difficulties with their friends. It is always reassuring when someone else has similar difficulties as you, and as Tommy has Barth syndrome, he can tell the children all about it.

The puppets were introduced to a number of UK Barth boys at our most recent Clinic (September 2014) and were very positively received by the boys. The show includes child-friendly conversations about medication, exercise tolerance, fatigue, and help in class with the addition of some fun jokes too... "Barth syndrome — does that mean you have to have a Bath every night urrgh," and opportunities for the audience to interact and ask questions. The first few performances have already been booked and will take place in the next couple of months.

This is an exciting project that enables us to reach wider audiences. It is just the beginning of using novel, age-appropriate communication tools to continue our theme of educating and empowering boys and men with Barth syndrome. Working alongside our teenage boys, Dani will develop a comedy sketch to be used in secondary schools as her next project.

Specialist Dietitian Reflects on BSF's Conference...

By Nicol Clayton, Specialist Dietician, NHS Barth Syndrome National Service, Bristol, United Kingdom



Nicol Clayton,
Specialist Dietician

This was my third conference, and with a week packed with clinics, presentations, posters and workshops, it promised to be a fulfilling one. Starting the week joining Dr. Kelley for the metabolism and nutrition consultations is always a highlight for me; being with Dr. Kelley is not only educational but also gives me an opportunity to hear directly from the families about feeding issues around the world and to be able to compare and contrast the treatment of these between countries. As always, Dr. Kelley and I continue to swap blood results, growth charts, and approaches to diet after the conference.

Presenting our UK findings on feeding problems and body composition on Thursday was also a really special experience, when I was able to show our current understanding and treatment of dietary problems and outline the holistic long-term dietary programme needed to support families through each life stage and each medical challenge. In the nutrition workshops, we explored how the overall day-to-day management of diet, mealtimes and supplements can impact on family life, and Mums and Dads helped each other in finding workable solutions to problems — even if this was to accept that things can't be changed immediately but may get better with time. Sometimes the unscheduled talks are the best, and thank you to all those parents who approached me just to talk and open up about what meals are

like in their house. Likewise, meeting the men with Barth syndrome and listening to their stories, as well as their thoughts and feelings about food, was invaluable and helped to reinforce my treatment methods of building a relationship with food for life.

Our dietary programmes are not fully developed yet, but each gap highlighted presents an exciting opportunity to pull together and merge the work and thoughts of the many great therapists involved in Barth syndrome worldwide. It was, therefore, wonderful to be able to discuss with Dr. Stacey Reynolds her exciting work on the sensory aspects of feeding and, along with Dr. Consuelo Krieder, to start to talk about programmes to treat this. At a meal kindly hosted by Dr. Matt Toth and BSF for the Kennedy Krieger and UK NHS multi-disciplinary teams, I was lucky to sit next to Dr. Hilary Vernon and Brittany DeCroes, and we had time to really talk about

(Cont'd on page 23)

Specialist Dietitian Reflects on BSF's Conference...

(Cont'd from page 22)

treatment, share ideas, explore differences and forge relationships for the future. Dr. Todd Cade's work provides vital evidence that feeds directly into the dietary and exercise advice we give to our boys and men. It was great to hear his latest findings on exercise and substrate metabolism and to be able to talk with him one to one about the practicalities of this on diet.

For every question answered at the Conference, I now have ten new ones. More than anything, the best thing about the Conference is the buzz of really wanting to work on making a difference — no matter how small, and now knowing lots of people I can reach out to in order to help. I feel that we get ever closer to being effectively one worldwide alliance of carers, families, boys and men.



UK round-up at the Conference. *(Photo courtesy of Sarah Bull 2014)*

BSF 2014 Conference — Assisting with Research and Reuniting with the BSF Family

By Sarah and Dave, Parents of two boys with Barth syndrome, Bristol, United Kingdom



Ashley (age 11) participates in Dr. Cade's research study.

We first attended the Barth Syndrome Foundation Scientific, Medical and Family Conference in 2004, and ever since then we have wanted to go back, but for one reason or another haven't been able to make it. Luckily for us, 2014 was our time.

Participation in Research

Our journey began with a seven-night stop at St. Louis, Missouri. Our sons, Kai and Ashley, were invited to take part in a research study conducted by Dr. Todd Cade. Todd was also looking for siblings who could help with the study, and our eldest son, Corey, gladly offered his services.

We were told what the research was for and what the tests would involve, and the boys agreed. Although they were very excited to be taking part, they were also very nervous about the blood tests and about how they'd cope with the exercise part. In Kai's words, "It wasn't as bad as I thought it would be, and some parts were actually quite fun!" The tests were scheduled for the mornings, leaving the afternoons and evenings free for some sight-seeing and adventures, which were plentiful in the area.

Some of the tests were energetic, like riding an exercise bike whilst connected to breathing apparatus. Some were fun, like being scanned by some weird and wonderful machines. Some of the tests weren't quite so exciting and involved lying down, watching TV and relaxing for a few hours as breath samples were taken at regular intervals.

(Cont'd on page 24)

BSF 2014 Conference — Assisting with Research and Reuniting with the BSF Family

(Cont'd from page 23)



Kai (age 13) participates in Dr. Cade's research study. (Photos courtesy of Sarah 2014)

A few blood samples were also required, which is where Todd's team had to earn their money. The boys can be a bit mean when it comes to giving away their blood, but the team was fantastic, and with the help of a few bits of specialist equipment and some expertise, the samples were taken. It made a change to see Corey being put through the same experiences his brothers go through and for him to appreciate and realise what it can be like to live with a condition that needs special care.

The whole team was fantastic, but a special mention has to go to Kay Bohnert who was absolutely amazing. Not only did she plan our journey from start to finish and schedule all the appointments, she also went out of her way to make sure we were all comfortable and happy with what was going on. The whole week ran like clockwork, even when we had to reschedule a day due to illness. We spent our last evening at the local pizza place with everyone involved with the study which is where we said our farewells and prepared for our flight to Tampa for BSF's Conference.

Welcomed Back with Open Arms

We arrived in Clearwater, and it was wonderful to see so many 'old' friends again. Even though 10 years had passed, we were recognised and welcomed back with open arms. We bonded instantly with many 'new' families and can honestly say we have made some lovely friends. It was great finally to put faces to the names that we regularly see on the listserv.

Having the venue at a holiday destination worked well for us, as the boys were able to recharge their batteries by chilling with new friends at the pool after a day of clinics. It also gave us plenty of opportunities to socialise with the group outside of clinics and discussions. Both Dave and I feel very humbled to have been a part of such an amazing experience. We are truly grateful to the many people who made this event possible and to the doctors and scientists who took time out from their busy lives for us.

Over the course of the week, I think we all encountered every emotion possible. Everyone has a story to tell and listening to others will always touch my heart. Having said that, we also laughed so much that we cried, especially when one of the scientists thought Dave was also a scientist and was quizzing him about things he had never even heard of. The look on her face when Dave finally admitted he didn't have a clue what she was talking about was priceless. The only bad part of the Conference was having to say goodbye. We hope it's not another 10 years before we are able to return again.

Conference Inspires Fundraiser Terri

By Terri Allison, Volunteer Fundraiser, Barth Syndrome Trust

I was very keen to go to the Barth Syndrome Conference for a few days, mostly to put faces to the names I have heard for so many years. I also wanted to meet up again with Shelley Bowen who was so inspirational when she attended our first volunteer workshop in England some years ago. I was overwhelmed by the professional way the venue was set out with TV screens showing what was on where in the hotel and the very large area dedicated to the Barth families. It was a pleasure to meet Dr. Steward and his team from Bristol. I was delighted to learn of the huge steps they had taken to improve the lives of those boys and men with Barth syndrome.

I found the last morning after the lunch very moving, when families who had attended the Conference for the first time spoke of its impact on them. It motivated me to continue with the grassroots fundraising I have been doing for the last 10-11 years. A young father spoke so well from his heart about how he felt part of such a huge family now and his confidence in his son's condition was lifted by the information he had gleaned from the weekend. His wife supported this and spoke briefly too of her feelings. They were followed by a young woman, whose brother has Barth syndrome. She was about to embark on marriage and raise a family. She had brought her boyfriend along in order that he be prepared for the chance that they too might have a son with Barth syndrome. She spoke so well and was so full of hope and fight that I was humbled by her spirit. As always, I am in awe of the families who live daily with this condition and their constant battle for a better future. My heart is with them all.

Terri has been fundraising for the Trust almost since the beginning. She has raised thousands of pounds for 'the boys' and has encouraged many of her friends to help.

President's Report BSFCa

By Lynn Elwood, President, Barth Syndrome Foundation of Canada



Emcee Bob, Adam & Lynn...
as Adam draws his Mom's winning ticket for the BBQ!
(Photo courtesy of BSFCa 2014)

As this has been a Barth Syndrome Foundation (BSF) Conference year, I will focus much of my report on that important week. Barth Syndrome Foundation of Canada (BSFCa) was once again very involved in the Conference. Lois Galbraith was part of the steering committee, coordinated the travel, accommodations, and logistics for the Science and Medicine presenters and worked at the registration desk. Devoted volunteers knitted sweaters for the Barth bears, mittens and scarves which were sold at the Conference with proceeds going to BSFCa. Silent auction items and contributions to the family gift bags were also provided by BSFCa.

We funded travel and accommodations for two Canadian scientists to present their research findings at the Conference, sponsored the very well attended Poster Session, a breakfast for all attendees, and the popular photo booth at the Friday evening social event. It was truly an inspirational week, and we were delighted to help make it happen.

Chris Hope, Susan Hone and others have been working hard at getting our new website up and running. It is in the testing stage now and you will soon see the modern, easy to use look of our new site.

I would like to close on a personal note. My son, Adam (now 24), and I were privileged to attend the Conference again this year. We have attended every conference since the first one and will do everything we can to get to them all. This trip we do together every second year continues to be very special to both of us, and is the best gift we can give each other. I have never seen Adam as comfortable as he is during this week. He is among friends and family from all over the world. The week lets him be himself, learn and grow, enjoy the laughter, and face the fears among people who accept and understand. The same is true for me. Not only do I get a week of time away and bonding with my son, I also get the chance to be among friends and my Barth family who understand what I am facing, accept me and help me through the challenges. Whether I meet the families for the first time or have known them for years, the bond and the support from this group is incredible. It doesn't stop at the families either. I had some great discussions with scientists and physicians. I am truly inspired and very excited about the work they are doing. It seems like the rate of progress is accelerating and we are getting close to recommendations and treatments that can really help in the daily lives of our affected guys. Together, the Conference gives us a chance to learn, laugh, dance, help advance the research, and enjoy the time with our Barth affected guys. It was an outstanding week that renewed my inspiration and touched my heart.

AGM Meeting — Eating the Expenses Instead of the Profits!

By Christine Hope, Treasurer, Barth Syndrome Foundation of Canada

Our annual general meeting (AGM) was held in early May this year. Once again, we would like to thank Ian Morris and Jones DesLaurier Insurance for letting us use their office space. As usual, the business portion of the meeting covered the activities and finances of the previous year and the plans and budget for the current one. As the various board members gave their reports, members asked questions and made comments along the way, keeping everyone involved in the discussion. For variety and ease of understanding, the finances were represented using jelly beans, instead of paper graphs. This way, we could actually eat our expenses!

A good portion of the meeting was employed to describe and explain the New Canada Not-for-Profit Act which will come into effect October 2014. All Canadian charities must get a continuance to comply with this Act by that time or they will be dissolved. BSFCa has been diligently working with a lawyer to ensure that we will meet all of the new requirements. One of the major items in this process was to overhaul our by-laws. At the meeting, President Lynn Elwood explained the changes in the by-laws and the reasons for them. They were then approved by the members, and we are now well on our way to completing the process and getting this rather tedious job done.

As we hope you know, the BSFCa remains proud to function entirely by volunteers (including the board and executive). We are very grateful for all of the time and energy people have exerted to help us to achieve our vision. For the last couple of years, we have taken the opportunity at our AGM to thank and honour some special volunteers for their dedication and hard work. This year, we chose the trio of Paula, Lindsay, and Natalie Sisson. We are very thankful to have the three of them on our team to help with this newsletter, creating awareness and various other jobs that they can be counted on at all times.

(Cont'd on page26)

AGM Meeting — Eating the Expenses Instead of the Profits!

(Cont'd from page25)

After the meeting and some social time, the fun part of the day began. This year, as an activity, we chose in-door glow-in-the-dark mini golf. Instantly, little coloured glowing balls went flying everywhere, occasionally even into the holes they were destined for. The day was rounded off with a delicious meal at a nearby restaurant. Once again, it was wonderful to see everyone, and to do some catch up.

SUMMARY OF FINANCIALS FOR THE YEAR ENDED DECEMBER 31, 2013

| | |
|------------------------|----------|
| Revenue | \$57,888 |
| Operating Expenses | \$44,379 |
| Research Grant Funding | \$ 9,648 |
| Net Revenue | \$ 3,861 |

A Decade of Golf Fun and Significant Progress for Treating Barth Syndrome

By Lois Galbraith, Volunteer, Barth Syndrome Foundation of Canada

Ten Barth Syndrome Foundation of Canada (BSFCa) golf tournaments have allowed us to conduct further research and give hope and encouragement to our special young men world-wide.

Our golfers, volunteers and donors have *“made a difference!”* In the decade of golf fun we have raised \$200,000.00 and our research grant contributions have been a total of \$230,000.00. Mighty impressive!! Many charities toss the word ‘research’ about, but with your help and support, the research into Barth syndrome has made great advances that have helped Barth families. For the first time, there are efforts underway to test a pharmaceutical drug for treating Barth syndrome (bezafibrate). The plan is to work together to perform a clinical trial with volunteers from Canada, the US, and the United Kingdom.

This past summer, the BSFCa contributed in significant ways to the 7th International BSF Scientific, Medical & Family Conference in Clearwater Beach, FL. Five of our Canadian men attended, took part in research and participated in educational sessions and social events. Be sure to read their first-hand thoughts and impressions about this important event (see page 28).

At the Conference in June 2014 there were presentations and discussions about specific therapies. We heard about enzyme replacement therapy, lipid replacement therapy, and gene therapy for treating Barth syndrome. This means that researchers are “translating” the scientific progress made with help of the BSF Research Grant Program (since 2002) into clinical practices. Again, very impressive!!

Your support of these golf tournaments has *“MADE A DIFFERENCE!”*



Lois Galbraith with early bird draw winner, Jim.



Ryan, Adam and Robert show their appreciation!

From the Heart

By Carol and Bruce Wilks, Volunteers, Barth Syndrome Foundation of Canada



Carol and Bruce Wilks.

We are very long-time friends of Les and Lois and have been a part of their family circle so have had first-hand knowledge of Barth syndrome through their grandson, Adam. Our first involvement with the Foundation was helping Lois with little tasks preparing for the golf tournament. Before we knew it, Bruce and I were at the golf tournament, and not being golfers, were put to work. Bruce was stationed at the Hole in One, and I was handed a camera to take foursome pictures. We are now in our tenth year at the tournament. It turns out that my quiet husband is very good at building awareness. He spends the day talking with folks and informing them about Barth syndrome.

A few years ago, Lois mentioned that the Foundation was in need of help with bookkeeping, and the next thing I knew, I was a member of the executive and their bookkeeper. Funny how that happens when Lois is a friend! Les and Lois's dedication and passion somehow just rubs off on a person!

Now that I am a member of the executive, Bruce is pulled into all of our fundraising endeavours. He grins and bears dances with loud music as well as everything else we drag him into for Barth syndrome. We are both happy to be part of such a great group of people with the common goal of enhancing the lives of these boys and young men.



Gifts of Love

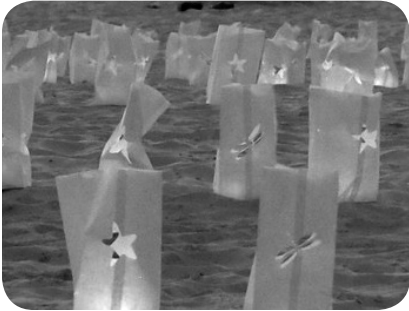
By Christine Hope, Treasurer, Barth Syndrome Foundation of Canada

The Barth Syndrome Foundation of Canada wishes to gratefully acknowledge the support of our donors' collective donations. It is only with the help of the many generous individuals and companies that we are able to continue to function. While we have a variety of fundraisers, we have also been blessed with donations made in honour and in memory of individuals. We would like to acknowledge these special people who are a great inspiration to us.

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Illuminating the Skies to Honour our Guys

By Susan Hone, Secretary, Barth Syndrome Foundation of Canada



I was talking with Shelley Bowen from the Barth Syndrome Foundation (BSF) prior to its international Conference and asked if there was anything I could take off her plate. She mentioned she needed someone to use an exacto knife to cut out over 300 dragonfly and starfish shapes on paper bags for a luminary project she had in mind. After laughing at her and asking if she was serious and did she know what was involved in doing this, she said she was quite serious.



Okay Shelley... I have it covered; I will make your vision a reality. Next was to convince my daughter, Jessica, that this would be a good project for her to do on her electronic die cutter I gave her for Christmas. With her on board, I purchased the supplies, dropped off 500 white bags at her house and thanked her. Once we saw the finished project, I started imagining how good it would look on the beach at night, and of course, they would be placed to look like the BSF logo.

I never realized the impact this one project was going to have on members of our Barth family or myself. The dragonfly has become our symbol to represent those who have died due to Barth syndrome, and we had one dragonfly bag for each person we knew who had died. The starfish represented those currently living with Barth syndrome. We had 160 dragonflies and 180 starfish. I was overwhelmed by the numbers. I started thinking about all the boys and men I had met over the last 14 years. I had to get this task right.

They looked amazing! Seeing everyone follow the bagpiper and drummer around the logo in the sand on the beach and placing the lights in the luminary bags was an image I will not forget for a long time. The emotions of the group, the smiles, the tears, the flashing of cameras told me that Shelley's idea was one of her best, and I am so pleased to have had a part in making it a reality.

Thank you to the numerous people who helped me with the set-up and clean-up, I couldn't have done it without you. Special thanks to my daughter, Jessica, who I nagged every day until she had the bags cut out. She was able to see all her work at her first conference ever. We have her hooked, she will be back again.

Barth Guys Speak Out — First Hand Impressions of the Conference

Adam: The fact that just outside the hotel there was so much, so close was great. It was like a sense of freedom. I appreciated the fact that the clinics were set up nicely and that I was able to get everything done in one day. Dr. Kelley's session "Men of Barth" was excellent. He was very encouraging to us older guys.

Jared: I am unable to properly convey my feelings and thoughts. Even though I am not able to participate in many of the activities, the Barth Syndrome Conference is extremely important to me. I have friends that I look forward to meeting every two years, and also, since my cerebral palsy is so much more obvious than the Barth syndrome, the Conference serves to remind everyone who takes care of me, that I'm doubly special, and not to get complacent about this dangerous component to my health.

Robert: For me, the best part of the Conference, aside from seeing old friends and meeting new ones, was the amount of information willingly offered to the families and affected individuals by the doctors and scientists attending alongside. The fact that the

information about the research being done was presented in such a way that could be understood by the families really helped prevent any non-alcohol related headaches. Also, I appreciated the fact that the doctors made themselves available after the sessions so that if we did not understand or if we had questions about things we wanted elaborated on.

Ryan: I was nervous about making a presentation to the Science & Medicine panel on the first day, but I did enjoy the talks and compliments from the scientists and researchers later during the Conference. For me, attending the Barth Syndrome Conference this summer was like coming home to family!!

Travis: I find the week of the Conference involves so much and it is so great to meet new friends (Ollie, Morgan & Josh) and to visit with old friends again. This is like a family reunion to me.

Thank You and ... Welcome!

By Florence Mannes, Chair, Association Barth France



During the past four years, Barth France has organized many various events around the country in order to increase awareness of the disease and raise funds, including poker tournaments, golf tournaments, Gospel concerts, Barth-designed holiday cards, vintage car rallies, all about truffle evenings, photo shoots..., not to mention constant participation in marathons, triathlons, Ironman or bike-and-run.

All this requires the involvement of many people, always ready to give time and energy, to move forward, day after day. Working in the shadows are men and women taking care of the accounts, communications, the journal, newsletters, the blog, the website, the Facebook page and Twitter account, just to mention those...

Each event requires the involvement of highly devoted teams, such as:

The **Poker Tournament** team. Our main partner, Groupe Partouche, provides the professional equipment and the croupier students volunteering for the evening. Some set up the tables and chairs, the decorations and the bar. Other partners provide - free of charge - drinks and sandwiches that are sold by volunteers. Different partners donate prizes for the winners.

The fifty singers of the **Gospel Colors Choir** come to Paris, at Church St. Honoré d'Eylau, to perform an awesome concert. The parish priest and church members, more welcoming year after year, make this project possible. The sacristan keeps the place open and arranges the lights during the show. The kids, in charge of the flyers, make sure the church is packed.

The **Golf Tournament** wouldn't be what it is without the dedication and generosity of both the director of the Golf de la Bretesche and the director of the Hôtel du Golf de la Bretesche and their teams. Besides organizing the whole tournament, such an event also requires promoters to get prizes, from their own companies or local businesses.

At a **Flea Market**, how would anyone expect to sell trinkets worth 1€ a piece and earn 2000€ at the end of the day — if it wasn't for the courage of a friend? He's able to mobilize his folks and collect their treasures within a few weeks. Thanks to him, many others join the team that loads and unloads a huge hire-truck, which is ready at 6 in the morning, to set tables, arrange everything and sell alternately, second-hand clothes, books, toys and dishes.

Not only does Barth France organize its own events but also benefits from generous donations from other associations. Once again, it wouldn't be possible without the kindness and involvement of the presidents and members of those associations: the triathlon clubs throughout France, the Rotary Club, Inner Wheels...

Thanks to them and their time and energy, Barth France was directly associated with a triathlon and benefited from the registration fees, shared a tremendous omelette à la truffe with a hundred generous guests, and even participated in a vintage car rally!

Barth France is also supported by several corporate foundations. The association was brought to their knowledge by members who worked for these companies and were willing to promote it and ready to defend it in front of a jury.

Collecting funds to finance medical research is one of our main goals, but Barth France also works to raise awareness about Barth syndrome. To that purpose, more than 200 amateurs have already worn the colors of Barth France, for one race or many; to run just five miles or to finish an Ironman. Each runs at their own speed, in their own way, to make sure everyone sees the blue heart logo. You can even see it on the outfits of entire local teams who have chosen to wear Barth France, encouraged by a few athletes who support our cause.

Finally - I would say, we are most grateful to our team of doctors because a cure is the true purpose of Barth France. In addition to their consultations, their on-calls, their own medical projects, they support Barth France. They travel to talk about the syndrome, they visit us during our events, and they remain at our side as we move forward.

(Cont'd on page 30)

Thank You and ... Welcome!

(Cont'd from page 29)

THANK YOU ...to Alexis ,Alice, André, Anne-Lise, Anne-Sophie, Anthony, Antoine, Arnaud, Arthur, Aude, Benjamin, Benoit, Bérengère, Bob, Bruno, Caroline, Cédric, Claire, Cléa, Cybelle, Damien, Didier, Eric, Estelle, Eugénie, Fabrice, Florence, François, Françoise, Frederic, Henry, Henry-Pierre, Hichem, Jacques, Jean, Jean-Bernard, Jean-Louis, Jean-Luc, Julie, Julien, Laure, Laurent, Madeleine, Marc, Marine, Martine, Matthieu, Michel, Nicolas, Olga, Olivier, Pascale, Paul, Pierre, Pierre-Romain, Romain, Sébastien, Severine, Stéphane, Stéphanie, Thierry, Valérie, Victor, Vincent, Xavier, Yannick, Yohan...and all of those we may have forgotten...not to forget more than 200 runners / triathletes and 800 donors! Nothing would be possible without all of them!!

SO JOIN US! Sportsman or not, young or not-so-young, active or less active, in Paris or someplace else on Earth, you can also help us move forward. Collecting funds is a big thing but we need teams to imagine and promote new events, as bold as they may be. You're free for the day? You're free for an hour? Contact us : Barth France recruits!



(Top) Barth France members before the Ironman France Nice in June 2014.

(Bottom) Philippe and Raphael gave high-fives to Barth France runners at the Paris Marathon.



Power of Kindness



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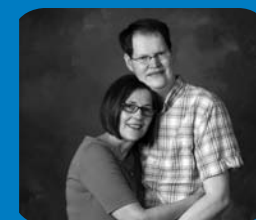
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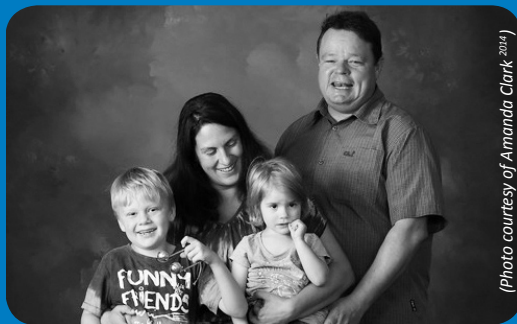
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(Photo courtesy of Amanda Clark 2014)

(L-R) Leo (age 7), Sonja, Valentina and Gregor



(Photo courtesy of Amanda Clark 2014)

Oliver (age 22)



(Photo courtesy of BTrust 2014)

Kai (age 13), Peter (age 27) and Ashley (age 11)



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Travis, age 19 & Kai, age 13



Jared, age 20



Ryan, age 22



Adam, age 24



Robert, age 28

(Photos courtesy of BSFCa 2014)



Barth Syndrome Foundation

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Website: www.barthsyndrome.org

Barth syndrome (BTHS; OMIM #302060)

A rare, serious, genetic disorder primarily affecting males. It is found across different ethnicities and is caused by a mutation in the *tafazzin* gene (*TAZ*, also called G4.5), resulting in a complex inborn error of metabolism.

Though not always present, cardinal characteristics of this multi-system disorder often include combinations and varying degrees of:

- **Cardiomyopathy** (*usually dilated with variable myocardial hypertrophy, sometimes with left ventricular noncompaction and/or endocardial fibroelastosis*)
- **Neutropenia** (*chronic, cyclic, or intermittent*)
- **Underdeveloped skeletal musculature and muscle weakness**
- **Growth delay** (*growth pattern similar to but often more severe than constitutional growth delay*)
- **Exercise intolerance**
- **3-methylglutaconic aciduria** (*typically a 5- to 20-fold increase*)
- **Cardiolipin abnormalities**



Tyler (age 11)

For more information, please visit Barth Syndrome Foundation's website:
www.barthsyndrome.org