



Cracking the *Mysteries* of Barth Syndrome

...at our 2006 International Conference

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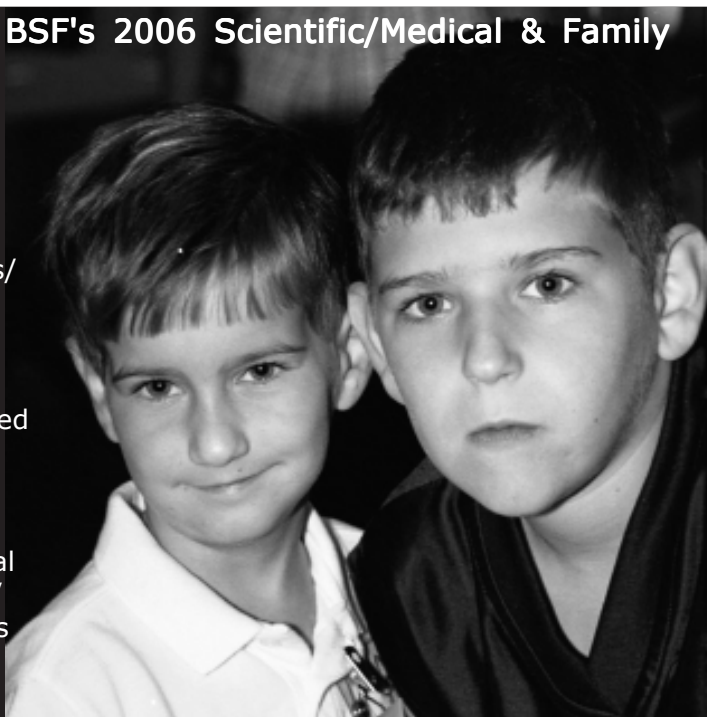
Who Should Attend BSF's 2006 Scientific/Medical & Family Conference?

- Any health care professional including: scientists, researchers, pediatricians, family physicians, school nurses/nurse practitioners, physician assistants and EMS, OT/PT personnel

- Family and friends affected by Barth syndrome

- Teachers, coaches

- Anyone who has a special interest in cardiac/hemo/neuro/metabolic disorders



Two of the many 'faces' of Barth syndrome. In each issue, we'll feature another 'face' of Barth syndrome.

In July 2006, the Barth Syndrome Foundation (BSF) will bring together the largest number of individuals interested in Barth syndrome internationally. Join us at our 2006 International Scientific/Medical and Family Conference, which will be held at Disney's Coronado Springs Resort, located in Lake Buena Vista, Florida.

Our participants will include treating physicians, involved research scientists, and affected families. As we have done so successfully in the past, we will have two simultaneous tracks for this meeting. In addition, clinics will be held on July 4-5, 2006, where all affected

individuals will be seen by physicians/clinicians who are most familiar with Barth syndrome.

The simultaneous sessions for both families and physicians/research scientists will be held on July 6-8, 2006. (For more detailed information, we refer our families to page 4 and the scientific/medical community to page 5.)

AGENDA

July 3	Family Reception
July 4-5	Clinics
July 6-8	Scientific & Family Sessions

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Katherine R. McCurdy – *ex officio*

Science and Medicine
Barth Syndrome Foundation, Inc.
New York

Changing the Future

By Valerie "Shelley" Bowen, President

Dear Friends,

The publication of BSF's newsletter marks a time when we, as an organization, take time to pause and reflect upon our accomplishments of the previous six months, and project forthcoming events to the stakeholders of our organization. The progress of BSF has only happened as a result of the commitment of the recipients of this publication. We are where we are because of the countless hours of our volunteers, the financial contributions of those who believe in our cause, and the talented advisors who have guided us along the way.

The truest statement that could be made about BSF and all of our affiliate organizations is that we exist because Barth syndrome exists. BSF was born in response to the needs of those affected by this disorder. Not so long ago, I reflected upon how BSF has made an impact not only in the lives of those who are affected, but also in the world of science.

Imagine being told that your child has Barth syndrome and you learn there is no one else to speak with who is in your same position; there is no research being done on the disorder and the disorder you have just learned about is considered fatal. Imagine typing "Barth

syndrome" in a search engine of the Internet and coming up with -0- results rather than -240,000- results. Imagine calling organizations where you think you could learn more about this disorder only to learn that no one had ever heard of the disorder (organizations such as the American Heart Association {AHA}), The National Health Services

in the UK, The National Institutes of Health (NIH) and the Center for Disease Control (CDC) in the US. It is difficult to consider this, but for some of us this was an all too true reality. This reality was not acceptable to us, so we set out to change the future, and we did.

Now we have created a forum where, with the click of a send button from anywhere in the world, families can not only commun-

icate with each other, but also with experts from around the world who are informed about the various components of the disorder. Now a diagnosis of Barth syndrome is no longer considered a fatal diagnosis. We are now partnering with leading health organizations around the world, and we are cited as a model organization for rare disorders. BSF is the only focused global source of funding for research in Barth syndrome. Family Services now provide resource materials and support in five languages other than

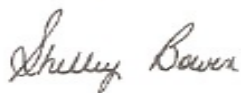
" Our capacity to deliver services, fund research, promote awareness and expand our efforts has been possible because of the generosity of others who embrace our mission..."

(Cont'd on page 3)

English (French, Italian, Spanish, German and Dutch). Biennial educational symposia and clinics are held representing a consortium of scientists, doctors and affected families. Families receive resources to aid them with their journey, without assessment of dues.

We have not wiped Barth syndrome off the face of the earth. However, through our continued efforts we are rising up to meet the needs of those affected by this disorder. As we have grown, the services we provide to meet these evolving needs have and will continue to become more complex. Our capacity to deliver services, fund research, promote awareness and expand our efforts has been possible because of the generosity of others who embrace our mission and are committed to our vision. As you read this newsletter, we hope that you too will see how we continue to change the future through your many contributions of resources.

Thank you,



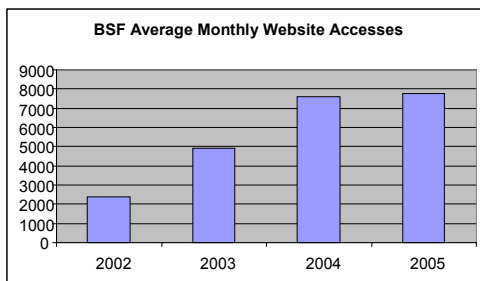
Shelley Bowen
President
The Barth Syndrome Foundation



Barth Syndrome Foundation *on the Web*

By Lynn Elwood, Chair, Technology

The Barth Syndrome Foundation website is one of the key ways that families and physicians find out about Barth syndrome and the Foundation. Over the years there has been a significant increase in the number of hits on the site each month.



are now in the process of working through a completely new website with an updated look and improved organization. We're very excited about this project and are anxious to unveil it to the public. Watch for the new website to go live in 2006.



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BSF's newsletter is designed for educational purposes only and is not intended to serve as medical advice. The information provided within this newsletter should not be used for diagnosing or treating a health problem or disease. It is not a substitute for professional care. If you suspect you or your children may have Barth syndrome you should consult your health care provider.

All submissions and correspondence regarding the newsletter should be directed to Lynda Sedefian at: Lsedefian@barthsyndrome.org.

2006 Conference ~ A Camaraderie of Families and a Distinguished Medical Team

By Jan Kugelmann, Chair, Conference Committee



Left to right: Mary Kate, Lee, English & Eliza

Surround yourself with the magic of Walt Disney World and join us for our 3rd International Scientific/Medical & Family Conference. Mark your calendar for July 3-8, 2006 and reserve your room at Disney's Coronado Springs Resort, located in Lake Buena Vista, Florida. This en-

core location was chosen because of its affordable rates (\$99.00/night), family friendly atmosphere, and the dedicated volunteers who live close by. Most importantly, we chose this location again because it was a great success in 2004, and we were able to focus on BSF initiatives, such as establishing a Biorepository and a medical database.

We have added many new discussion topics to the agenda, including updates on genetic testing, research initiatives, and how the science applies to your day-to-day lives.

- Talk one-on-one with the leading experts in Barth syndrome.
- Learn what all the lines and colors mean during an EKG/ECG & echocardiogram.
- Meet the researchers and discuss the complexities of, and new developments in, the research funded by BSF.
- Get the latest treatment information in order to make informed medical decisions.
- Discuss basic cardiac anatomy and physiology.
- Gain a better understanding of living with the complex symptoms of Barth syndrome and learn coping mechanisms/strategies from those who know best – the other families living with this disorder.

We are fortunate to once again have our fantastic Barth syndrome experts conducting clinics. The benefits of these clinical sessions are twofold: No where else is there such a gathering of experts knowledgeable of this multi-system disorder who will be able to answer your questions; and the data collected will be compared to other individuals with Barth syndrome – not your “garden variety” cardiomyopathy patient!

The clinics offer a time for families to interact and learn about the Foundation - who we are and what we do. There is ample time for the kids to play games, create crafts and form new friendships.

"The camaraderie between the boys, their families, the medical team, counselors and volunteers changed my life. ...The work that goes into these conferences is tremendous and the results are a miracle!"

~ Sandy Shantzen
Friend/volunteer

The conference will give children from around the globe a chance to make connections. Friendships will be rekindled; children will get to know others they can relate to, and new friendships will begin to grow. Teens can expect plenty of time between sessions for additional activities or just hanging out.

In return for your commitment to attend our 2006 conference, BSF will deliver satisfaction. This unique opportunity delivers a customized educational symposia about Barth syndrome, face-to-face time with experts and families alike, and memories that will last a lifetime. **To register, please visit our website at www.barthsyndrome.org. Updates will be made periodically.**

Magical Express – Take advantage of the latest innovations in Disney's legendary commitment to service and convenience: *Disney's Magical Express!* This complimentary shuttle and luggage delivery service conveniently takes you from the airport directly to your Walt Disney World® Resort hotel.

**SCIENTISTS and PHYSICIANS, PLEASE REGISTER NOW FOR:
The Barth Syndrome Foundation Scientific and Medical Conference
July 6-8, 2006
Coronado Springs Resort in Buena Vista, Florida
"Cracking the Mysteries of Barth Syndrome"**

There is much still to be learned about the complexities of Barth syndrome (BTHS). On July 6 and 7, 2006 at the 3rd International Barth Syndrome Foundation Scientific and Medical Conference, the world's leading researchers and clinicians will give presentations on many topics that continue to perplex even the most seasoned investigators. Experts in multiple fields (see list below) are designing an innovative, thought-provoking agenda that will address what is now known and explore what is not yet understood. Speakers have been invited, and it promises to be a very stimulating and productive meeting.

There also will be a poster session. The general **Call for Posters** will be issued soon, and some travel awards will be granted for the presenters of the best of these. We are particularly interested in encouraging young investigators (doctoral and post-doctoral students) to consider participating in this. New insights into any aspect of Barth syndrome are sought. Please consult the Barth Syndrome Foundation website (www.barthsyndrome.org) for details.

On July 8, physician attendees will participate in working sessions to develop the first treatment guidelines for Barth syndrome. The collective experience of the attendees will become a necessary reference for every physician treating a Barth syndrome patient. Your involvement and insights are critical!

Major Agenda Topics:

Functions of the Tafazzin Protein

Miriam L. Greenberg, PhD — organizer
Professor, Department of Biological Sciences, Wayne State University; Associate Professor of Oncology, Barbara Ann Karmanos Cancer Institute, Wayne State University; Associate Dean, College of Liberal Arts and Sciences, Wayne State University, Detroit, MI

Dr. Greenberg's well-known research interests focus on genetic control of mitochondrial membrane biogenesis in yeast, in particular.

Michael Schlame, MD — organizer
Department of Anesthesiology, NYU School of Medicine and Cornell University, New York, NY

Dr. Schlame's clinical focus consists of pediatric and adult critical care, cardiothoracic anesthesia and pediatric anesthesia. His research interests include mitochondrial energy metabolism, cardiolipin, pulmonary surfactant, mechanisms of multiple organ failure and cardiomyopathy.

Cardiac Aspects of Barth Syndrome

Jeffrey A. Towbin, MD — organizer
Chief of Pediatric Cardiology; Director, Phoebe Willingham Muzzy Pediatric Molecular Cardiology Laboratory; Professor, Pediatrics, Cardiovascular Sciences and Molecular and Human Genetics, Baylor College of Medicine

Dr. Towbin is a well-known pediatric cardiologist whose major clinical interests include cardiomyopathy, cardiovascular genetics and cardiac transplantation.

Hematological Aspects of BTHS

Colin G. Steward, BM, BCh, MRCP, FRCpCh, PhD — organizer
Bristol Royal Hospital for Sick Children, Bristol, UK

Dr. Steward is Reader in Stem Cell Transplantation at the University of Bristol, England and is interested in genetic diseases affecting the blood and bone marrow.

Other Clinical and Scientific Issues of BTHS

Richard I. Kelley, MD, PhD — organizer
Professor of Pediatrics, Johns Hopkins University School of Medicine, Director, Division of Metabolism, Kennedy Krieger Institute; Baltimore, MD; Staff Physician, The Kennedy Krieger Institute; Director, Intermediary Metabolism and Clinical Mass Spectrometry Laboratory

Dr. Kelley is an expert in metabolic diseases and has been involved in the treatment of more cases of Barth syndrome than any other individual in the US.

To register for this conference, we ask that all participants (families, doctors & scientists) register on-line at www.barthsyndrome.org.

Barth Syndrome Foundation *Launches* Major Science and Medicine Fund

By Steve McCurdy, Chairman and CFO

The Board of Directors of The Barth Syndrome Foundation, Inc. has launched an eighteen month effort to raise between \$5-7 Million to insure the stability and continuation of its Science and Medicine programs for the next decade. Commitments in amounts totaling over \$1 Million have already been received and planning is underway to identify sources for the remaining funds. Steve McCurdy, BSF's Chairman describes the need for such a fund and BSF's plans to raise such a significant sum.

When the founding directors of The Barth Syndrome Foundation, Inc. (BSF) sat down to plan out the future of BSF just five years ago, we faced the most important decision we would make about BSF. Should BSF focus exclusively on family support, or should our vision expand to include increasing awareness among physicians and then expand still further to include scientists and researchers? Having just come from a meeting of family members in Baltimore where we didn't have enough money for tables and chairs, the idea that we would one day be awarding research grants internationally and attending meetings at the National Institutes of Health in Washington DC seemed like a dream.

But it has happened! In the five year history of BSF, we have raised just over \$1,750,000 in contributions. We have awarded 14 research grants in three years for a total amount of just under \$500,000, with seven more presently under consideration. We have held two BSF International Family and Scientific Conferences, assembled a world-class group of scientific advisors, are a familiar presence at scientific and medical conferences, and have now been joined by affiliates on three continents. We have a

rapidly growing BSF family community that will soon exceed 100 families as active members... a critical statistic. We have an enviable record of success to date, largely because we planned carefully and refused to have small dreams. Today, we are still driven by our ultimate dream:

"A world in which no one will suffer or perish from Barth syndrome"

The search for treatment, and ultimately a cure will require a sustained effort over time, and the cooperative effort of every one of the key groups in the BSF community: affected families, volunteers, donors, physicians and scientists. We understand that this race is a marathon, not a sprint.

"The search for treatment, and ultimately a cure will require a sustained effort over time, and the cooperative effort of every one of the key groups in the BSF community."

Long Term Investment Areas: Bio-repository & Medical Database

The key elements of our plan include the creation of a bio-repository and medical database to capture DNA and data that will be crucial to future research. We are currently in negotiations to establish and fund both of these facilities in cooperation with a major university and research institution, and we expect them to be in place before the Third International BSF Conference in July of 2006.

Reaching the mark of 100 active family members in BSF was our inspiration to move ahead with these facilities. Knowing that BSF has created and continues to maintain a central source of data and samples from 100 affected families, clearly distinguishes Barth syndrome from other rare disorders in the competition for research attention. Once begun, this program must be sustained over the long term at an estimated ten year cost of \$1.4 Million.

Research Grants

As previously noted, BSF has now established an increasingly well-known and successful

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research grant program. Our intent has always been to fund research in small awards to: a) increase the number of scientists studying Barth syndrome, who will b) publish their results, and c) commit to use their results to enhance their requests for larger awards from larger, better funded institutions such as the NIH and American Heart Association. The strategy is working. BSF is attracting more and more researchers from around the world to focus their work on Barth syndrome. Since the founding of BSF, the average number of articles published annually in peer-reviewed journals is up almost 400%, in comparison to the average of the previous ten years. BSF researchers have won and are now seeking much larger follow-on grants from both the NIH and AHA. Our intent is to double the size of our annual grant program starting immediately, and over the next ten years we expect to award approximately \$3.5 Million in research grants.

Multi-Disciplinary Collaboration

Barth syndrome is a complex, multi-system genetic disorder. Its treatment requires experts in an array of fields who do not typically work closely together, and the research required to isolate the cause and find a cure is equally complex. BSF's unique approach to our biennial Conference is an outgrowth of this reality. Specialists in every discipline – both clinicians and bench scientists – gather to listen to each other's findings and experiences and map out the future of research into Barth syndrome. Collaboration is encouraged and designed into these sessions. Connections are constantly being made to research findings in related areas of cardiology, neurology, hematology, and likewise, Barth research may already be providing clues to solve problems in other areas as well.

BSF will build on these unique and successful biennial meetings with similar smaller collaborative workshops for clinicians and scientists in off-years. Like the larger BSF conferences, these workshops will feature focused discussions across multiple disciplines on cutting edge research relevant to a deeper understanding of Barth syndrome. Science is moving rapidly, and we will need an estimated \$1.12 Million over the next decade to insure the

interdisciplinary collaboration that is so essential to long-term success.

Increased Awareness

We have made excellent progress increasing awareness of Barth syndrome among physicians. There are now more labs certified around the world to make a confirmed diagnosis. Where six years ago, the phrase "Barth syndrome" did not produce a single citation on Google, today it produces over 240,000 references – a direct result of BSF's work.



(L-R): Leonie, Roby (16 yrs.), Ron & Danny (15 yrs.) onboard HMAS Farncomb Submarine @ Garden Island Submarine Base & Training Center in Western Australia. (Tour courtesy Starlight Foundation.)

Despite our efforts however, Barth syndrome is still largely unknown within the medical community. Diagnosis can still take years following birth – years that statistics show is the most dangerous period for a boy carrying the Barth gene. The complex metabolism of a person affected by Barth syndrome can make otherwise standard treatments for symptoms very dangerous. For some families and physicians, this situation is even more serious where English is not the primary language. At this point, the majority of information about Barth syndrome is in English. BSF has an obligation to continue to expand our awareness programs; to reach more physicians and affected families in more languages in countries around the world. In addition to a physical presence at medical conferences, we are enhancing our internet presence, and need to serve families and physicians equally in multiple languages. We believe the cost of these programs will amount to approximately \$250,000 over the next ten years.

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Update on Barth Syndrome Foundation's Scientific and Medical Advisory Board

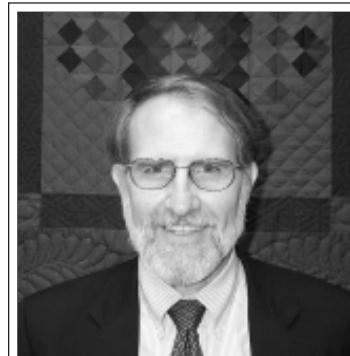
By Kate McCurdy, VP, Science & Medicine



Kate McCurdy, ex officio, BSF's SMAB

Our Scientific and Medical Advisory Board (SMAB) is vitally important to BSF. We have been blessed to have a first-class team of specialists representing fields critical to Barth syndrome. Each member has made important contributions and has helped launch our young organization.

Wayne State University in Detroit, MI. She presented at our last two international Barth conferences. Having received one of BSF's first research grants, she gave a wonderful and insightful talk to the boys and young men with Barth syndrome about how scientific research is conducted. An expert



Richard I. Kelley, MD, PhD, Chairman, BSF's SMAB

on phospholipid metabolism in yeast, with a wealth of knowledge about cardiolipin, she (along with Dr. Michael Schlame) will lead the biochemistry section of the 2006 Scientific and Medical Barth conference.

The initial four-year terms of our founding SMAB members concluded earlier this fall. As with any vibrant group, evolution is an inevitable and positive occurrence that can result in new perspectives, ideas and energy being introduced.

We gratefully thank Dr. Mary Ann Bonilla and Dr. Annette Feigenbaum for their SMAB service. From their own fields of expertise and from different geographic regions, they have shared their experience and knowledge with us. Their assistance to BSF is much appreciated, and we hope they will continue to be closely involved with our foundation and our mission.

"I think it is wonderful that you have attracted such outstanding individuals to BSF. I sincerely look forward to working with Drs. Greenberg and Steward, and I wish them the best in their association with BSF."
~ Grant Hatch, Ph.D.

Simultaneously, we are extremely pleased to welcome two new SMAB members. Both have been very involved with BSF already and have become friends of many of us. It is great to have them join the organization as official advisors.

Miriam L. Greenberg, PhD is a Professor of Biological Sciences and the Associate Dean for Research in the College of Arts and Sciences at

Colin G. Steward, BM, BCh, MRCP, FRCPC, PhD is a Reader in Stem Cell Transplantation at the University of Bristol in England. Through his interest in genetic diseases affecting blood and bone marrow, he has become very familiar with Barth syndrome. He started a Barth clinic at the Bristol Royal Hospital for Sick Children and has become a key advisor to BST in the UK. He too has presented at our last two conferences and will lead the hematology section of the Barth conference in July 2006. He is well known to us, not only as a wonderful physician, but also as one who eloquently discusses the likelihood of underdiagnosis of Barth syndrome.

Please join me in thanking all of the founding SMAB members, especially Dr. Bonilla and Dr. Feigenbaum, for their generous service to BSF and in welcoming Dr. Greenberg and Dr. Steward officially to our SMAB team.



Barth Syndrome: What are the Options for Testing *before* Birth?

By Rebecca L. Kern, M.G.C., Genetic Counselor, Division of Metabolism, Kennedy Krieger Institute

I've been asked to review the ways of testing for Barth syndrome before birth. Some tests give you a direct answer about Barth syndrome, while others provide their own unique benefits, such as identifying gender. Science has come a long way, and as you'll see in this article, it keeps evolving. I'm going to walk you through the currently available tests and discuss some that are still considered investigational.

The most commonly used method for prenatal diagnosis of Barth syndrome is testing the baby's DNA from a chorionic villus sampling (CVS) or cultured amniocytes from an amniocentesis. The DNA is tested for a previously identified mutation in the *TAZ1* gene. CVS is typically performed between 10 – 13 weeks gestation and an amniocentesis between 15 – 20 weeks. Both of these tests provide an adequate sample for DNA testing of the baby, but they also carry risks to the pregnancy because they are invasive. Risks for each center vary, but, in general, CVS has a risk of 1/100 for miscarriage and amniocentesis, 1/200.

Another option that is growing in use is called preimplantation genetic diagnosis (PGD). PGD allows for testing of oocytes (eggs) or embryos even before they are implanted in the womb with the aid of in vitro fertilization (IVF). IVF is an assisted reproductive procedure where fertilization of the egg occurs outside the body in a controlled setting.

There are two types of preimplantation diagnosis - polar body biopsy and embryo biopsy. Both methods involve harvesting oocytes from stimulated ovaries and then testing either polar bodies or embryos. Polar bodies are by-products of egg formation and contain the same DNA as the egg. An embryo is a post fertilization 6 – 8 cell mass, from which 1 – 2 cells are removed for PGD.

Each type of analysis has advantages and limitations. Polar body testing focuses on the maternal contribution, and is an earlier method of testing. Generally, polar body testing is

performed in any case where the female partner of the couple carries the gene of interest, like Barth syndrome. Embryo biopsy involves testing the embryo directly and therefore, one can look at maternal and paternal contributions. However, in some cases, embryo biopsy has a higher chance of misdiagnosis or error. Often the lab will analyze both polar body and embryo cell in order to provide the highest level of accuracy possible. Generally, polar biopsy is between 95 – 98% accurate and embryo biopsy is 90 – 95% accurate. Yet, even though offered clinically, PGD is a research-based test and it does not replace CVS or amniocentesis, the current standard-of-care.



Gender is an important question when it comes to testing for Barth syndrome. We all know that only boys will have Barth syndrome, so finding out if the baby is a boy can be an important piece of information. There are two standard ways to find out the gender of a baby: you can take a look at the fetal sonogram and hope that the baby isn't shy (not always accurate), or you can look at the baby's chromosomes from a CVS or amniocentesis sample.

Most parents who have children with X-linked conditions would like to know the gender before undergoing invasive testing. However, based on the currently available options, there is no guaranteed way to do this. There are two tests on the horizon that may help in this area.

First, there is a test that looks directly at fetal cells collected with a cervical swab similar to a Pap smear. This test uses a special technique to separate maternal and fetal cells and then uses fluorescent in situ hybridization (FISH) to detect the chromosomes. FISH is a process in which probes containing the same DNA as the

(Cont'd on page 10)

What are the options for testing before birth?

(Cont'd from page 9)

chromosomes combine with their matching chromosome and they show up different colors. For example, X chromosomes would be red and the Y would be blue. If the baby were a male, you would see one red signal and one blue signal; if female, you would see two red signals. This test is not widely available and still considered investigational. In many physicians' minds it has not been proven as a safe and accurate test, but research of the test continues and the potential for early gender identification is there.

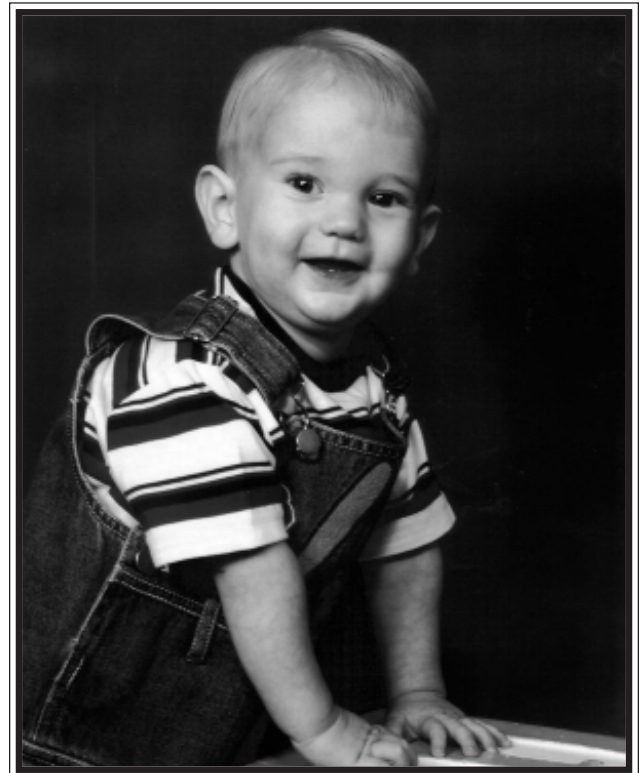
Another test, currently being offered in Europe, is called SRY gene amplification. Basically, this test looks for a specific gene (SRY) that is found only in male fetuses in the mother's blood. Because the mother's and baby's blood are in close proximity in the placenta, small amounts of cell free fetal DNA can enter into maternal circulation.

One might think if fetal DNA can be detected, why isn't the TAZ gene itself tested? This wouldn't work, because, if the mother is a carrier, free DNA from her would carry the same mutation as the potentially affected baby and one wouldn't be able to tell whose DNA you were testing.

As a result, this new fetal DNA method allows testing only for paternally inherited traits (from the father) such as the Y chromosome, which would make the baby a boy. As with any test, there are false positives and false negatives. In this particular case, one needs to be concerned about fetal cells from previous pregnancies that could remain dormant in maternal blood. Even so, most research studies quote a 95 – 100% specificity rate, meaning that 95 – 100% of people who are truly free of a specific disease are correctly identified as such by the test. This test offers obvious benefit for our Barth parents, but it is still considered experimental in the United States, and to my knowledge is not being used clinically.

Overall there are many choices when it comes to testing for Barth syndrome before a child is born. Most of what is currently available is

associated with risks for loss, but there are several tests in development that have implications for at least gender identification, and perhaps more as the technology continues to improve. Only time will tell...



"Having already lost a son to Barth syndrome, we felt that prenatal testing was essential. Once we determined that Benjamin was also affected, we were able to schedule prenatal monitoring of his heart function and to assemble a team of well-prepared specialists in advance of his birth.

This contributed immeasurably to Benjamin's care and progress during his first few months of life."

~ Keli

NIH Research Initiatives

Seeking Applications

In addition to the vast investigator-initiated research that is supported by the National Institutes of Health (NIH), research in some specific areas is solicited by various NIH institutes from time to time. Applications for these usually are accepted for February 1, June 1 and October 1 deadlines every year. **The following ongoing NIH initiatives are particularly relevant to Barth syndrome.**

Exploratory and Developmental Research Grants for Investigations in Rare Diseases (R21)

(Initiative number: PA-03-171)

Purpose: To encourage exploratory and developmental research projects by providing support for the early and conceptual stages of projects that represent novel approaches to the understanding, treating, and preventing rare diseases in the areas of heart, lung, and blood disease, as well as sleep disorders. **Please visit:** <http://grants1.nih.gov/grants/guide/pa-files/PA-03-171.html> for more details.

Chronic Illness Self-Management in Children

(Initiative number: PA-03-159)

Purpose: To solicit research related to improve self-management and quality of life in children and adolescents with chronic diseases. Children with a chronic illness and their families have a long-term responsibility for maintaining and promoting health and preventing complications of the chronic disease. Research related to sociocultural, environmental, and behavioral mechanisms as well as biological/technical factors that contribute to successful and ongoing self-management of particular chronic diseases in children is encouraged. **Please visit:** <http://grants2.nih.gov/grants/guide/pa-files/PA-03-159.html> for more details.

Tools for Zebrafish Research

(Initiative number: PAR-05-080)

Purpose: To encourage investigator-initiated applications designed to exploit the power of the zebrafish as a vertebrate model for biomedical and behavior research. **Please visit:** <http://grants.nih.gov/grants/guide/pa-files/PAR-05-080.html> for more details.

Chronic Fatigue Pathophysiology and Treatment

(Initiative number: PA-05-030)

Purpose: To support investigator-initiated research on the epidemiology, diagnosis, pathophysiology, and treatment of chronic fatigue syndrome (CFS) in diverse groups and across the life span. **Please visit:** <http://grants.nih.gov/grants/guide/pa-files/PA-05-030.html> for more details.



Travis, 10 years old, has been learning the guitar for 3 years. He takes lessons once a week and plays guitar with his Dad as much as he can.



Ben, 8 years old, makes a statement in his pirate outfit.

'Faces'
of Barth
syndrome

What is

Barth Syndrome?

Barth syndrome is a rare but serious X-linked recessive disorder, in which the clinical effects of the *G4.5* (or *TAZ1*) gene mutation are manifested only in males. The characteristics of Barth syndrome include the following in varying degrees, even within the same family:

Cardiomyopathy: Heart muscle weakness. This, combined with a weakened ability of the white blood cells to fight infections, represents the greatest threat to boys with Barth syndrome.

Neutropenia: Reduction in the number of "neutrophils," a type of white blood cell that is extremely important in fighting bacterial infections. The neutropenia may or may not follow a regular cycle, but in either case, it puts Barth boys at an increased risk of serious infections.

Muscle Weakness and General Fatigue: All muscles in a Barth patient, including the heart, have a cellular deficiency which limits their ability to produce energy, causing extreme fatigue during activities requiring strength or stamina – from walking to writing to growing.

Growth Delay: Most boys with Barth syndrome are below average in weight and height, often substantially so, until the late teenage years.

Early diagnosis is key to survival for Barth syndrome boys. Those in whom the diagnosis of Barth syndrome is missed have only a 30% chance of living through the first few years of life. With a proper diagnosis and appropriate treatment of all the symptoms at an early age, however, these boys have an 85-90% chance of survival. This is why awareness of Barth syndrome is so important.

Peer-reviewed articles recently added to BSF's Bibliography which are relevant to Barth syndrome

Committee on Infectious Diseases and Committee on Fetus and Newborn. **Revised Indications for the Use of Palivizumab and Respiratory Syncytial Virus Infections Immune Globulin Intravenous for the Prevention of Respiratory Syncytial Virus.** Pediatrics 2003;112;1442-1446.

POSITION STATEMENT (ID 2003-03). **Use of palivizumab in children with congenital heart disease.** Paediatr Child Health Vol 8 No 10 December 2003.

Schlame M, Ren M, Xu Y, Greenberg ML, Haller I. **Molecular symmetry in mitochondrial cardiolipins.** Chem Phys Lipids. 2005 Sep 7. PMID: 16226238 [PubMed - as supplied by publisher].

Cohen N, Muntoni F. **Multiple pathogenetic mechanisms in X-linked dilated cardiomyopathy.** Heart 2004, 90: 835-841.

Davey KM, Parboosingh JS, McLeod DR, Chan A, Casey R, Ferreira P, Snyder FF, Bridge PJ, Bernier FP. **Mutation of DNAJC19, a human homolog of yeast inner mitochondrial membrane co-chaperones, causes DCMA syndrome, a novel autosomal recessive Barth syndrome-like condition.** J Med Genet. 2005 Aug 3; PMID: 16055927 [PubMed - as supplied by publisher].

Tajima T, Satoh K, Okuhara K, Tsubaki J, Fujieda K. **Hypomagnesemia in a patient with Barth syndrome.** J Pediatr Endocrinol Metab. 2005 May;18(5):523.

Brandner K, Mick DU, Frazier AE, Taylor RD, Meisinger C, Rehling P. **Taz1, an Outer Mitochondrial Membrane Protein, Affects Stability and Assembly of Inner Membrane Protein Complexes: Implications for Barth Syndrome.** Mol. Biol. Cell. 2005; 16: 5202-5214.

Dimauro S, Gurgel-Giannetti J. **The expanding phenotype of mitochondrial myopathy.** Curr Opin Neurol 2005 (Oct;185):538-42.

Spencer CT, Byrne BJ, Gewitz MH, Wechsler SB, Kao AC, Gerstenfeld EP, Merliss AD, Carboni MP, Bryant RM. **Ventricular Arrhythmia in the X-linked Cardiomyopathy Barth Syndrome.** Pediatr Cardiol. 2005 Oct 18; PMID: 16235007 [PubMed - as supplied by publisher].*

Zhong Q, Greenberg ML. **Deficiency in mitochondrial anionic phospholipid synthesis impairs cell wall biogenesis.** Biochem Soc Trans. 2005 Oct;33(Pt 5):1158-61.

F Gonzalez, J-J Bessoule, F Rocchiccioli, S Manon, and PX Petit. **Role of cardiolipin on tBid and tBid/Bax synergistic effects on yeast mitochondria.** Cell Death and Differentiation (2005), 1-9. Hennekam RCM. Invited Comment. The Challenge in Hidden Treasures: A Never Ending Story. **American Journal of Medical Genetics 2004, 126A:331-332.**

F Gonzalez, F Pariselli, P Dupaigne, I Budihardjo, M Lutter, B Antonsson, P Diolez, S Manon, J-C Martinou, M Goubern, X Wang, S Bernard and PX Petit. **tBid interaction with cardiolipin primarily orchestrates mitochondrial dysfunctions and subsequently activates Bax and Bak.** Cell Death and Differentiation (2005), 1-13.

*Supported by grants that have been awarded by BSF

Barth Syndrome Foundation, Inc. 2005 Grant Cycle

BSF, Inc. has received seven research grant applications (from four countries) in the 2005 grant cycle. Final funding decisions regarding these proposals will be made by January 31, 2006.

*To learn more about BSF's grant program, visit: www.barthsyndrome.org

Prospects for Gene Therapy in Barth Syndrome

By Barry J. Byrne, M.D., Ph.D., Cardiology Director, Department of Pediatrics, Shands Children's Hospital



One of the key objectives of modern molecular biology and biochemistry is to understand the mechanisms of a disease at the most basic level. Such a detailed understanding of the disease process is an important part of designing specific therapies for the disease.

Over the past 20 years, tremendous advances have been made in dissecting a disease process down to what is often a single causative factor, such as a defective gene. The opportunity to repair or replace the defective gene has been the holy grail of genetic medicine and is commonly known as gene therapy (the term gene transfer is more realistic since it does not imply a successful treatment). Since the therapeutic agent in this strategy is highly specific to the defect in the patient, the expectation is that the approach may be more successful than other types of medicine which treat certain aspects of the disease but do not affect the root cause, a defective gene. As of today, the promise of gene therapy has been unfulfilled in humans except for one partially successful example in children with immune deficiency. While application to human subjects has been difficult and slow, there is considerable cause for optimism based on an impressive array of animal studies which demonstrate success in disease models. So what are the ingredients of a successful strategy for gene therapy of a given disease?

- 1) A well understood pathophysiology;
- 2) Knowledge of the disease causing gene and its function;
- 3) A predictive animal model;
- 4) Clinically relevant means of delivery of the gene to target tissues.

Is Barth syndrome (BTSH) a suitable candidate disease for this approach? BTSH is an important candidate for a molecular medicine approach to treatment. First, there are well defined target

tissues, such as skeletal and cardiac muscle. Although there is more to learn about the function of TAZ, it is clear that mutations in this gene are responsible for BTSH, and therefore a new copy of the gene would be a potential therapy. Gene replacement in an X-linked or autosomal recessive condition is much more amenable to a gene therapy approach than a dominant condition where the therapeutic would need to remove a gene product. An animal model is key in the further development of gene therapy or any therapy for that matter. Some work can be done with cell culture systems, but current practice would require proof of concept experiments in an animal model before human clinical studies would be initiated.

The last criterion relates to feasibility of successful gene transfer in human subjects. Over the past several years, significant advances have been made in understanding ways to achieve long

"Gene replacement in an X-linked or autosomal recessive condition is much more amenable to a gene therapy approach than a dominant condition ... In summary, gene therapy for BTSH is a realistic option for management of the disease in the future."

~ Barry Byrne, MD, PhD

lasting gene transfer in cardiac and skeletal muscle. Most recently, these strategies have become more achievable because of advances in the field of virology and gene therapy vector design (a vector is the disabled form of a virus used to carry the therapeutic gene). The foremost concern in developing a gene therapy approach to a disease is that early phase studies are safe. All studies are conducted in accordance with the strict guidelines of the FDA and offer the best safety profile that we can establish. In summary, gene therapy for BTSH is a realistic option for management of the disease in the future. Efforts underway for gene therapy in other forms of cardiomyopathy will help guide the way to a gene therapy for BTSH.



Calendar of Events

November 2005

- 4-5 BSFCanada '06 Planning Mtg.
- 13-16 BSF booth at American Heart Association (AHA); Dallas, TX
- 15 BSF Exec. Committee Mtg.

December 2005

- 8 BS Trust Trustees' Mtg.
- 10-13 BSF booth at The American Society of Hematology 47th Annual Meeting & Expo; Atlanta, GA

January 2006

- 19 BSF Board Mtg.
- 19 BSFCanada Board Mtg.
- 31 BSF 2005 Research Grant Awards announced

February 2006

- 8-12 BSF booth at Ninth Annual Update on Pediatric Cardiovascular Disease (a/k/a Cardiology 2006); Scottsdale, AZ
- 13-19 Children's Heart Week
- 16 BSFCanada Exec. Committee Mtg.
- 21 BSF Exec. Committee Mtg.

March 2006

- 18-19 BS Trust Volunteer Workshop & Trustees' Mtg.
- 21 BSF Exec. Committee Mtg.
- 23 BSFCanada Exec. Committee Mtg.

April 2006

- 20-22 BSFCanada Annual Board Mtg.
- 21-23 BSFAnnual Board Mtg.

May 2006

- 16 BSF Exec. Committee Mtg.
- 18 BSFCanada Exec. Committee Mtg.

June 2006

- 22 BSFCanada Exec. Committee Mtg.

July 2006

- 3-8 BSF Int'l Scientific/Medical & Family Conference; Lake Buena Vista, FL
- 18 BSF Board Mtg.



Bristol/BTHS Clinic



Florida Outreach



Canadian Outreach



Short break during Capacity Building Workshop

September 2006

- 19 BSF Exec. Committee Mtg.

October 2006

- 17 BSF Board Mtg.
- 18-21 35th Annual Child Neurology Society Mtg.; Pittsburgh, PA

November 2006

- 21 BSF Exec. Committee Mtg.

December 2006

- 9-12 The American Society of Hematology 48th Annual Meeting & Expo; Orlando, FL

Barth in the News

"Devoted gran's crusade for a cure"

~ Andover Advertiser, Nov. 18, 2005

"Bowling fundraiser to aid Barth Syndrome"

~ Straus Newspaper, Oct. 16, 2005

"Jean 4 Genes Day is part of the war against Barth Syndrome" ~ "Tiny jeans team with a mission"

~ Hampshire (UK), Oct. 6, 2005

"William's Story (2005)"

~ Jeans for Genes, Oct. 2005

"Perry Elks Lodge Plays Bingo for Barth Syndrome"

~ Local Lodges Online, Oct. 2, 2005

"Kilometers vreten in VS"

~ De Schaapskooi, Sept. 20, 2005

"The little boy with a big dream"

~ Woman's Own, Sept. 5, 2005

"Family hopes to raise awareness of rare disorder"

~ The Herald, July 27, 2005

"Emotional welcome for brave cherubs"

~ Western Daily Mail, July 4, 2005

"Genetic Diagnostic Tool Offers Hope for High Risk Couples Contemplating Pregnancy"

~ Daily News Central, Dec. 12, 2004

Fundraisers in Your Community

**Mini Horseracing Fundraiser
Black Tie Event (Barth Trust SA)**
Natal, South Africa ~ June 4, 2005

Quiz Night (BS Trust/UK)
Petersfield, UK ~ June 10, 2005

Dinner Party (BS Trust/UK)
Oakley, UK ~ June 11, 2005

**Biking Across America Tour
(BS Trust - Europe)**
July 2nd - August 8, 2005
Albert Wubs bicycled 5800km in 50 days, while Hanneke Blokzijl raised money amongst colleagues.

3-Peak Challenge (BS Trust/UK)
July 10, 2005

Quiz Night (BS Trust/UK)
Overton, UK ~ June 24, 2005

Belgian BBQ (BS Trust/Europe)
Jemeppe-sur-Sambre ~ Aug. 20, 2005

Sports Night (BSF, Inc.)
Brockton, MA, USA ~ Sept. 1, 2005
Hosted by Coach Ed Nottle of the Brockton Rox.

Great Scottish Run (BS Trust/UK)
Glasgow ~ Sept. 4, 2005

BSF of Canada Golf Tournament
Canada ~ Sept. 12, 2005

**Steinhatchee Race & Taste
(BSF, Inc.)**
Steinhatchee, FL, USA ~ Oct. 1, 2005

**Bristol Half Marathon
(BS Trust/UK)**
Bristol, England ~ Oct. 2, 2005

**Perry Elks Lodge Bingo Night
(BSF, Inc.)**
Perry, FL, USA ~ Oct. 3, 2005

**Support of Nat'l Jeans for Genes
Day (Barth Trust/UK)**
United Kingdom ~ Oct. 7, 2005

**4th Annual Barth Syndrome Golf
Tournament (BSF, Inc.)**
Merrit Island, FL, USA ~ Oct. 9, 2005

**Steinhatchee Harvest Festival
(BSF, Inc.)**
Steinhatchee Falls, FL, USA ~
Oct. 15, 2005



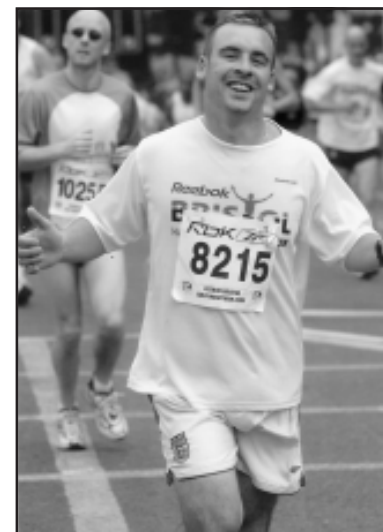
*Blue Lemonade Stand
built and donated to BSF
by Patty and Jim Zurbrick*



*Isabelle, who ran in the NY
Marathon for BS Trust,
and her friend Pio!*



Belgian BBQ



*Dave at the finish line
of the Bristol Half Marathon*

**2nd Annual Bowling Fundraiser
(BSF, Inc.)**
Warwick, NY, USA ~ Oct. 15, 2005

**Taylor County Forest Festival
Blue Lemonade Stand (BSF, Inc.)**
Perry, FL, USA ~ Oct. 22, 2005

**Isabelle's London Party
(BS Trust/UK)**
London, UK @ The Gate Restaurant
Oct. 27, 2005

Inaugural Poker Run (BSF, Inc.)
Merritt Island, FL, USA ~ Nov. 5, 2005

New York Marathon (BS Trust/UK)
New York, NY, USA ~ Nov. 6, 2005

Fashion Show (BS Trust/UK)
Oakley, Basingstoke ~ Nov. 10, 2005

**County-Wide BSF Family Fun Day
(BSF, Inc.)**
Perry & Steinhatchee, FL, USA ~
Nov. 19, 2005

**Oakley Infants Christmas Sale
(BS Trust/UK)**
Oakley, Basingstoke ~ Nov. 25, 2005

Christmas Fair (BS Trust/UK)
Overton, UK ~ Nov. 26, 2005

Poinsettia Sale (BSF of Canada)
Beautiful 8", 3 bloom poinsettia.
Contact: critter@barthsyndrome.ca

**BSF Wristbands for sale!
(BSF, Inc. & all affiliates)**
Show your support for BSF and wear
one of our new wristbands that read
"Grow Stronger".

For more information, please contact:
jkugelmann@barthsyndrome.org

**"Friends of Barth Quilt" Raffle
(BSF, Inc.)**
Raffle tickets are being sold for a
Queen/Full Size Quilt, handcrafted by
Nina Rivers and given to BSF as a gift
to help raise funds. Drawing to be held
@ BSF's 2006 International Conference.

Prices: 1/\$2; 6/\$10; 10/\$15;
15/\$20; 20/\$25 (Books of 10)

Contact: JOYLOC105@aol.com; or
Lsedefian@barthsyndrome.org

Science and Medicine Fund Launched

(Cont'd from pg. 7)

"Thanks to you our donors, scientists, doctors and volunteers ... with the creation of this fund and the prospect it offers for the future, we will have the one thing we truly need to keep us going - hope for a future free of Barth syndrome for our children."

The BSF Science and Medicine Fund

In order to insure that these crucial programs continue unabated for the next decade, we are committed to finding this funding over the next eighteen months, and the Board has authorized the establishment of a separate BSF Science and Medicine Fund toward this end. We have already received commitments for over \$1 Million from several strong supporters of BSF, including our stalwart Anonymous Donor. Also as a part of this effort, the Wilkins' family has established the 'Woody Varner Fund for Science and Medicine', in memory of Sue's father and John's grandfather. Woody Varner

was the much beloved President of the University of Nebraska. Sue, her Mother and Sister are approaching many of their and his friends to ask them to contribute.

We need everyone's help. We cannot expect to rely on a few volunteers to ask a few donors to help us reach our goal. If you are reading this, then you have already made some sort of contribution to BSF and no doubt have a connection with someone who is affected. In addition to your usual annual gift to BSF, please consider making an extra contribution this year and next to the BSF Science and Medicine Fund.

For those of us with children affected by Barth syndrome, a cure has always seemed little more than a distant dream. Thanks to you - our donors, scientists, doctors and volunteers - with the creation of this fund and the prospect it offers for the future, we will have the one thing we truly need to keep us going - hope for a future free of Barth syndrome for our children. Our distant dream feels a little closer!



Volunteer Capacity Building Workshop

In October of 2005 we hosted our annual capacity building workshop in Prosperity, South Carolina. During this time our program leads came together to discuss priorities and our plans for 2006. Leaders came from Canada, the US, the UK, and South Africa and spent three days discussing every detail of our plans for the future. I would like to commend these marvelous individuals for their continued commitment to excellence in all we do.

During our workshop we received training in communications from Susan Osnos, an independent communications consultant and former director of communications of Human Rights Watch, and in fundraising from Kate Golden, a consultant with Changing Our World, an organization that aids groups such as BSF in raising the funds that are so vital in executing our goals.

Participants in the Workshop: Sue Wilkins, Lynn Elwood, Kate and Steve McCurdy, Steve and Jan Kugelmann, Shelia Mann, Chris Hope, Leslie Buddemeyer, Shelley Bowen, Lynda Sedefian, Jeanette Thorpe, Michaela Damin

Organizers: Beverly Lever and Alanna Layton

Outreach Program

In 2005 the Barth Syndrome Foundation (BSF) embarked on a new approach to provide face-to-face contact with our families in various geographical regions, as well as promoting awareness about Barth syndrome and BSF within the medical community within those regions. This program was initiated in 2004 by Darlene Guasco in Brenham, Texas. The success of this program demonstrated the need to move forward to other global communities. The approach to each of these outreach meetings was as unique as the communities they serve.

To lead these outreach programs, Shelley Bowen traveled throughout the US, Europe, and the UK to promote awareness about BSF, BST, our

(Cont'd on pg. 17)

Outreach ... (Cont'd from pg. 16)

program priorities and desire to be in contact with families who have or may soon be diagnosed with Barth syndrome. BSF Canada held their second outreach meeting where many members met each other for the first time.

I would like to thank the organizers of these outreach meetings without whose leadership these gatherings would not have been a success: Joke van Loo, Eva and Nicolas Antomarchi, Michaela Damin, Casie and Scott Oldewage, Rosemary Baffa, Lynn Elwood

Cities visited: Mainland Europe: Amsterdam, The Netherlands, Paris; United Kingdom: Birmingham, Bristol, Romsey, Newcastle, London; USA: Salt Lake City, Utah; Philadelphia, Pennsylvania; Clearwater, Florida; Canada: Toronto



The People who Put the "Fun" in Fund Raising!

By Scott Oldewage, Fundraising Committee

As you can see on page 15, our dedicated fund raisers have been busy promoting Barth syndrome, increasing awareness and raising money for BSF, BSF Canada, BS Trust (UK/Europe) and Barth Trust – South Africa. At the most recent count, over 27 separate events or fund raising efforts have taken place in four countries since June of this year! Our families and friends have run marathons and half marathons, climbed the tallest peaks in the UK,



Bowlers at BSF's 2nd Annual Bowling Fundraiser in Warwick, NY

we are supported by an amazingly creative group! Several pictures accompany this article and the attached list of events – take a look and you will find the people whose efforts on our behalf make everything, including this newsletter possible!

In addition, we are beginning to have success asking corporate employers for their support. The Lake City Companies in Salt Lake City, Utah and its President, Ed Pace have raised and contributed more than \$10,000 on behalf of

Scott & Casie Oldewage and their son ... much of it through payroll deduction and matching programs.

American Express where Steve McCurdy works does the same thing, as does Bay State Gas where Tom Monahan works and Becton Dickinson where Liz Higgins works. Isabelle Lemette, a friend of Michaela Damin in the UK, works for Disney which has supported Isabelle's fund raising marathons on behalf of BSF, and there are many others too.

These companies and others want to be good citizens. If you work for a company, ask if they have a payroll deduction or matching gift program and if you can use their program to give to BSF.

Finally, for anyone in the US who would like to give a little bit on a regular basis, you can do so on-line by clicking the Networkforgood.org button on the BSF website donation page. Network for Good allows you to set up a monthly, quarterly or annual contribution to BSF, and charge it to your credit card. It couldn't be easier!

Thank you to all the people who have contributed, and thank you to all of our committed fund raisers... we could not do anything without you!



(L-R) Pete Kugelmann, Tom Tinsley, Dave Kugelmann, Matt Kugelmann and his son Robbie, major donor solicitors for BSF's Annual Golf Tournament in Merritt Island, Florida.



"Mystery Diagnosis"... and More

By Steve Kugelmann, VP, Awareness

Successes in our Awareness Campaign have never been better. As mentioned in the last issue, we have been expanding our exposure on several fronts. In September, the Bowen family story was taped for a TV segment on the Discovery Health Channel. The show is called "Mystery Diagnosis" and the segment is planned for airing early next year. Barth syndrome is featured as one of the segments during the 1-hour show.



BSF billboard at Texas/Fort Worth Int'l Airport, where Clear Channel Airports graciously donated the billboards as Public Service Announcement space.

After several months of discussions with the production company, we were able to convince them that families with Barth syndrome and the Barth Syndrome Foundation have a very compelling story that their audience

needs to hear. Stay tuned for more information.

At the recent American Heart Association Annual - Scientific Sessions meeting, BSF was present at the Dallas/Ft. Worth airport in Texas. We secured five locations at the airport for a 43-inch high x 69-inch wide poster. Clear Channel Airports graciously donated the billboards as Public Service Announcement space. While BSF was exhibiting at the AHA, a major magazine that is interested in doing a human-interest story on a rare disorder approached us. The correspondent's interest was heightened as she listened intently to a personal story about one of our boys and their family. Our networking machine was put into motion and plans are in work to continue to pursue this opportunity.

In the Czech Republic city of Prague, Dr Petr Losan kindly distributed BST materials at the European Society of Human Genetics conference. In the UK, newspapers, national magazines, television and radio have all recently run stories. Barth syndrome has gone from an unknown disorder to one that is more frequently recognized and diagnosed worldwide.

Lois Galbraith brings us yet another excellent example of working family connections:

"THE POWER OF THE CARD"

While out for an evening of dinner/music with the girls we came around to a discussion about Barth syndrome. I left my sister Carol with many details about the Barth Syndrome Foundation of Canada, our up-coming Golf Classic date and a business card.

Four days later my nephew Scott phoned to say he had gotten the BSF of Canada card and would love to golf with us BUT BETTER STILL he could help our Foundation!! It turns out that Scott works for Rogers Media (something his Aunt did not know) here in Canada and they publish the Medical Post, Patient Care, Pharmacy Post and Pharmacy Practice. These publications go out to about fifty thousand (50,000) physicians and several thousand pharmacists in Canada. He could arrange for us to have free BSF of Canada filler awareness ads in these publications. Naturally the team jumped into action and soon we had very professional ads ready. The first of these awareness ads are now appearing in doctors' and pharmacists' offices across Canada.

Praise be the little blue and white awareness tool and "The Power of the Card".

All of these opportunities have become reality because we will not give up until a treatment is available!



Busy Year for Family Services

By Christine Hope, Co-Chair, Family Services

This has been a busy year for Family Services. Our numbers have grown considerably, and we now have ninety-seven diagnosed living individuals and families in our database. It is always heartening when a "new" family contacts us. Our sentiment is often conflicted. We are pleased they made the decision to contact us, we are pleased to be able to help them, and we are pleased they have received a diagnosis. Conversely, we are never pleased to learn that another family has received a diagnosis of Barth syndrome. Increased membership numbers in the United States, Canada, United Kingdom and Europe is a clear indication that the hard work of our Awareness Team is paying off.

" Our numbers have grown considerably, and we now have ninety-seven diagnosed living individuals and families in our database."

~ Chris Hope

One of the main goals of Family Services is to provide up-to-date and accurate information to all families. To that end, we have had two main focuses this year. One important task was updating the Family Services' webpage. We have totally revamped that portion of the website, and have tried to make it easier to access and read the information. Thank you to Greta Develle and Lynn Elwood for getting the new and improved page up and running.

Many families have said that they want information that explains the various components of Barth syndrome in everyday words. Therefore, our second focus was to research and write two-page "Fact Sheets", reviewed and approved by expert doctors. After many hours of hard work, several completed documents are available on the website. There are a few more sheets in progress, and once completed they will all be combined in a booklet and sent to all affected families. Our plans for next year will be to get the sheets translated into several languages so that more families will

be able to take advantage of them. Shelia Mann and I would like to thank our committee members and co-authors, Susan Hone, Michelle Telles, Shelley Bowen and Karen Gordon. We'd also like to thank Dr. Barth, Audrey Anna Bolyard, R.N., Dr. Byrne, Dr. Cox, Dr. Gonzalez, Dr. Kelley, Dr. Spencer, and Dr. Strauss for their assistance.

Family Services continues to maintain the listserv, and currently we are lining up topics for next year. To give everyone ample time to read and ask questions without feeling hurried, it has been decided to extend the length of each topic from two weeks to one month. The listserv is still the best way to ask questions of the entire group, and posts to the listserv are always welcome, regardless of the official topic. We would be glad to hear from you regarding what topics you would like to discuss over the coming year.

Our big project for next year will be the 2006 BSF International Conference. We will be working with the conference committee to create an interesting and informative Family agenda. If there are specific topics you would like discussed at the conference, please let us know now so that we can plan to make this the most beneficial event possible.

We are working very hard in trying to keep our family database accurate, and would ask that you help us maintain it. If there are any changes in your information, please let us know. Shelia and I would be happy to hear from you at any time: smann@barthsyndrome.org
chope@barthsyndrome.org



Devoted grandmum Annick and Nicholas share a special moment! Annick is an active member of BS Trust's Family Service Team. (Photograph courtesy of Andover Advertiser, Hampshire, UK)

Enthusiasm works!

Inside a Barth Syndrome Trust Workshop

By Nigel Moore, United Kingdom

Panic set in as Saturday Sept. 17th neared. Lorna had been to a previous workshop and come back changed. Most unusual: the enthusiasm, the sudden interest in conquering computers, the long telephone calls – what had happened? This roped-in husband was about to find out. First impressions were auspicious. Could their hideaway in rural Hampshire, England, be the corrugated iron shack behind the Methodist Chapel? Inside was an eclectic gathering of parents, volunteers and the unsuspecting. Among the international itinerants were Jo van Loo from The Netherlands, and Steve McCurdy from the USA. Other intrepid travellers found their way there from London and Bristol. A strong local county contingent had been lured in by Annick, Michaela and Terri.

In the blur that followed, we were told what had been happening and in the heady atmosphere we made plans for the future. Chair Michaela outlined BST's history and major goals like attracting more and varied volunteers, helping families and one day finding a cure; quote 'everything we do is guided by our boys'. She also spoke about recent successes in raising awareness through articles in newspapers and magazines, television interviews and radio. Annick reported on Family Services' and the help and encouragement from BSF. Jerome, BST's Treasurer, was into money and where it's going. Terri revealed where it's coming from (See page 15 - Fundraising). Steve, Board Chair, talked about BSF's history, the need for more funds and lessons from BSF's experiences. Lorna enthused about publications work and handed out sample fundraising brochures and Family Services booklets.

Jo, European Rep, spoke on the expanding work of BST in Europe, up from 3 known families in 2000 to 17 today, co-operating with helpful



Michaela Damin, Nigel Moore, and Jo van Loo at BST's Volunteer Workshop

organisations, increasing coverage in the news media, fundraising, and the conference in April in Amsterdam. Europe is a challenge because of the range of languages encountered.

Lunch (by Rob – Mic's dad)!!!! Well-fed teams then went into brainstorming mode to identify future objectives before reporting back.

Exciting times lie ahead for BST. Awareness goals are direct mailings to doctors, more press coverage and posters in hospitals, medical conferences. Administration goals are to 'nap a secretary, get sponsorship for local printing of newsletter, create databases and research available resources. Family Services aim to complete all Registry Intake forms, finish social fact sheets, promote the International Conference, update BST website particularly with more European input, and get families more involved. In addition, plans for Europe include creating material in various languages, updates to translated websites, organising more meetings and increased fundraising. Publications team's goals are to support other committees with effective literature and continue close working with Lynda and her team at BSF. The Fundraisers plan more grassroots events and will seek corporate sponsorship and grants. Business over, time to eat, relax and bond.

Out of this eventful day came supercharged volunteers, faces to names, nuggets of information, increased waistlines and an overawed me. It was serious and fun, inspiring and perspiring, businesslike and informal.

BST/BSF really is an exciting place where ordinary people are doing extraordinary things. Join!!



Editor's note: Lorna and Nigel are now active members of our Publications Team.

Barth Syndrome Foundation of Canada

By Lynn Elwood, President

The Canadian Executive just completed our 2006 planning session. We did some reflecting on 2005 and quite a lot of planning for 2006. Looking back, we were amazed to see just how far we've come in a year. Here are some of the things we've accomplished in the last few months of this year:

We held an Outreach meeting which was attended by over 30 family members. Through this event, we found and met a new family with an affected 4-year old and one unaffected son, and we were able to get to know the oldest affected man in Canada.

We ran our first golf tournament. It was a terrific day with 100 golfers, great weather and lots of memorable moments. Some of the boys were able to attend, and they were a highlight as they were awarded hero medals. This was a huge undertaking, especially for organizers Cathy Ritter and Lois Galbraith. We are planning to hold the second annual golf tournament next year. Thanks to Cathy, Lois, our sponsors and all our supporters that helped us to make significant profits from this fundraiser. Special thanks to Mike Wilkins for coming all the way from Nebraska to attend.

We participated in a workshop with the Canadian Institute of Health Research and several other charity organizations. We were the smallest and newest organization and received praise for some of the projects we are involved in, and planning. We gained considerable knowledge about processes related to funding of scientific research in Canada and made some valuable contacts to work with as we grow.

We published 7 advertisements in the Medical Post and received positive feedback on them from physicians and others.



BSF Board (L-R) Karen Gordon, Cathy Ritter, Lynn Elwood, and Chris Hope, along with Lois Galbraith, Executive Assistant

We attended an Awareness conference in Los Angeles for the Child Neurology Society and had a good presence at the Canadian conference of Pediatric Cardiologists where Dr. Towbin gave a talk and we distributed material.

We have grown our circle of volunteers, friends and donors considerably over the year. We are very fortunate to have received many donations through the year that are helping us to plan expanded programs in 2006.

There are many exciting plans for the remainder of 2005 and 2006. We are putting together a Scientific and Medical Research Grant program and will share details of this as it is finalized. We are reaching out to new groups of physicians with our awareness programs, and hoping to participate in a Canadian conference. We are keeping in touch with our Canadian families and planning methods to find and attract other families and physicians in Canada. And of course, we continue to focus on the Barth boys and men.

Some of the key initiatives in the next few months will be around the 2006 BSF Conference in Florida. We're very much hoping to see all of the Canadian families there. We will be providing information for Canadian families about agencies they can contact to request assistance to attend the conference. We will also be helping with conference organizing and possibly financing some of the Canadian portions of it. We hope to see all of you at this important event.

Please keep in contact with us. We always love to hear from you. Our phone and fax numbers are unchanged, but please note our new address:

Barth Syndrome Foundation of Canada
1550 Kingston Road, Suite 1429
Pickering, Ontario L1V 6W9



The Barth Trust of South Africa ~ Year-End Update

By Jeannette Thorpe, Chair



I would like to start this update with a few very grateful thanks.

Firstly, to my small fundraising committee (featured above) who helped me put together a most spectacular evening of events on the 4th June 2005. This marked our first fundraiser for the South African affiliate.

To Margie Burnett, Penny Kneebone, Juanita Brown, Romaine Baker, Alison Longhurst, Dawn Ries and Amanda McVeigh – thank you for your dedication, talent and hard work.

Thank you to my publications specialist, Carol Jardine.

I am in awe of our guests that attended this fundraiser. Not only did they embrace the event with such enthusiasm, but they gave very

generously in support of our goals. Thank you all for investing in our cause. We managed to raise R129 000,00 (approx \$18,400.00 US)!

Through the generosity of our investors, I am able to send two South African specialists to the USA next year to attend our 2006 Scientific and Medical Conference. This will give them an opportunity to learn about Barth syndrome from our leading experts and in turn, they will be able to educate other South African doctors.

Lastly on this note, I would like to thank our many sponsors, and particularly, our main sponsor, Weddings and Functions.

Awareness:

1. BSF educational brochures were placed in the congress bags at six medical conferences this year.
2. We had two articles published (parent perspectives) and one abstract:
 - "Mother calls for doctors' help to fight rare disease." The Mercury (South Africa), April 2005.
 - "A child with Barth Syndrome." CME - The SA Journal of CPD, January 2005.
 - 11th Biennial Congress of the South African Society for Human Genetics.
3. Ongoing telephonic and/or e-mail communications to key medical personnel.

Regards, Jeannette Thorpe



Jeannette Thorpe (center), with mounted jockeys at the "Mini Horseracing" fundraiser held on June 4, 2005 in South Africa.



Jeannette Thorpe poses with jockeys at "Mini Horseracing" fundraiser.



History of a Grown-Up "Barth Boy"

By Johan Fioole, The Netherlands



"I consider myself to be very lucky because, although I have Barth syndrome, I lead a very happy life with my wife and two daughters. I even celebrated my 40th birthday ...I really feel that Barth syndrome changes your life, but does not have to stop you from living."

After that period, I grew up rather normally. Physically I was not very strong, and I was very small for my age. But besides that, I managed well in school and with my friends.

In the 70's/80's things started to change in our family. My oldest sister lost her son to an unknown disease. In 1983, her second son was born, and shortly after his birth he became very ill too. After some time, he was diagnosed with Barth syndrome. It also turned out that his brother died of the same disease.

For me every thing went well until the age of 33. Then my health deteriorated and I was diagnosed with symptoms of heart failure. That summer, my nephew died because of Barth syndrome. This also was the time when I became aware that our symptoms could be related. At that time a doctor who specialized in genetic disorders tested my DNA, and I too was diagnosed with Barth syndrome.

My name is Johan Fioole, and I live in The Netherlands. My journey with Barth syndrome starts in 1965, the year of my birth, a period in which no one knew what Barth syndrome was about. I have two sisters and three brothers. My oldest sister is a carrier of Barth syndrome, as is my mother, but the rest of the family is healthy.

Shortly after I was born, doctors found out that I had an enlarged heart that was not functioning well, and I was admitted to the hospital. I stayed for several months, and at the age of one, I returned home. At that point I was diagnosed with cardiomyopathy.

One of the reasons why I was having problems with my health was that I did not act in accordance with my physical condition, and I kept doing this for a long period of time. Now I take medicine to improve the function of my heart, and I take rest when I feel tired. This has made an enormous difference, and although I have my ups and downs, I feel rather well at the moment.

When I was diagnosed with Barth syndrome I visited several doctors, and one of them was Prof. Barth in Amsterdam. He told me of The Barth Syndrome Trust and suggested that I join. I was told that the Trust could help me learn more about Barth syndrome, and I could share my story with others and help them too. I followed his advice, and I am very happy that I did. Everything he told me was true, and I really feel that we can help and support each other.

Finally, I would like to mention that I consider myself to be very lucky because, although I have Barth syndrome, I lead a very happy life with my wife and two daughters. I just celebrated my 40th birthday in November, and I hope for many more years to come. I really feel that Barth syndrome changes your life, but does not have to stop you from living. When I read the stories on the

listserv, I notice that a number of our boys are getting older now, and I do hope that in some years we will not only be able to speak about our Barth 'boys', but also about our Barth 'men'.

Barth Syndrome Trust ... also has representatives in the following regions:

Northern Europe:

Mrs. Jo van Loo
(Languages supported: Dutch, English, German)
Pr. Brummelkampstraat 49
8191 XC Wapenveld
THE NETHERLANDS
jovanloo@barthsyndrome.org

Southern Europe:

Mrs. Eva Antomarchi
(Languages supported: French, Italian, English)
Les Acacias Bâtiment B Quartier La Sèbe
18 chemin Sainte Thérèse
04 000 Digne - les - Bains
FRANCE
eantomarchi@barthsyndrome.org



Barth Syndrome Sibling Spotlight!

By Jess Weiderspan

Below are the profiles of two of our fantastic BSF siblings. Please e-mail Jess Wiederspan at onionhater1979@yahoo.com with questions or comments.



Alanna Layton

Age: 26

**Name and age of
Barth Sibling:** Michael,
age 19

What is your educational background? I earned my masters degree in mass communication in May of this year.

Career goals: To work in public relations

My Favorite...

Movie: The Princess Bride

TV Show: Lost

Book: Toss up between "The Mists of Avalon" and "Wicked"

Food: Strawberries

Hobbies: Singing, playing guitar, reading, watching movies, spending time with my family

Something unique about me is: I sang in Carnegie Hall when I was 13

As a Barth sibling, I think the best thing about the Barth Syndrome Foundation is: We are no longer alone because of BSF. Siblings, parents, affected boys and other family members no longer have to feel isolated or like no one else understands what they are going through. We all have each other now.



Eliza McCurdy

Age: 11

**Name and age of
Barth Sibling:** Will,
age 19

What grade are you in? I am a 5th grader at Greenwich Country Day School

Career goals: To be a lawyer and to be a singer.

Favorite Movie: Grease

Favorite TV Show: Gilmore Girls

Favorite Book: Troubles Daughter and So B. It

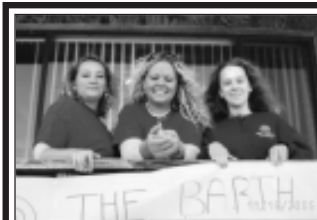
Favorite Food: Lobster

Hobbies: Sing, dance, act

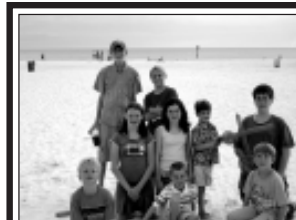
Famous person I'd most like to have dinner with: Jesse McCartney

Something unique about me is: I have a brother with Barth syndrome who is 6' 2" tall

As a Barth sibling, I think the best thing about the Barth Syndrome Foundation is: I have made a lot of good friends while being involved with BSF.



(L-R): Wendy Cruce, Melissa Sullivan, and Alanna Layton, volunteers at the County-Wide Fun Fest Day in Perry, Florida.




BSF's Outreach Program on the road bringing families and sibs together!

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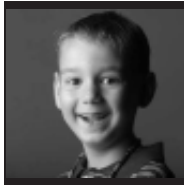
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Thank you for your patience as we continue to update our records!

Call for Conference Posters

Barth Syndrome Foundation Scientific and Medical Conference
July 6-8, 2006
Coronado Springs Resort in Buena Vista, Florida

The deadline for receipt of abstracts is Wednesday, February 1, 2006



What is my Diagnosis?

Doctor,
do you
know
enough

to diagnose my
disorder? Miss my
diagnosis and I have
only a 30% chance
of living to age 4
years.

Cardinal characteristics,
in varying degrees, include:

- Cardiomyopathy
- Neutropenia
- Muscle hypoplasia & weakness
- Exercise intolerance
- Growth retardation
- 3-Methylglutaconic aciduria
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Barth Syndrome Foundation, Inc.
P.O. Box 974
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Telephone: 850-223-1128
Website: www.barthsyndrome.org

The Barth Syndrome Foundation 2006 Scientific and Medical Conference Organizing Committee invites conference attendees to submit abstracts for poster presentations related to any scientific and/or clinical aspect of Barth syndrome. Posters should present: 1) information that is new and different, 2) novel insights into previously considered data, or 3) significant extensions of material presented previously. Abstracts will be peer-reviewed, and all proposals that are accepted will be scheduled as poster presentations.

The full Call for Poster Abstracts outlines the process for submission, including format, content, style and eligibility requirements. Please go to www.barthsyndrome.org for further details and for an application; they will be posted soon.

Some travel funding will be available, based on need and as well as the quality of the poster proposed. Completion of an additional form is required to apply for this funding. We particularly encourage young investigators (doctoral and post-doctoral students) to consider participating in this feature of the program.

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



Barth Syndrome
Foundation

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