Barth Syndrome:
On Track Toward a Cure

Sponsored by:

Barth Syndrome Foundation, Inc.
Barth Syndrome Trust (UK & Europe)
Barth Syndrome Foundation of Canada

Barth Syndrome Foundation®

www.barthsyndrome.org

4th International Scientific, Medical and Family Conference

July 21-26, 2008

An international meeting with sessions for bench scientists and clinicians as well as for affected individuals and their families

Belleview Biltmore Resort & Golf Club
Clearwater, Florida

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

Welcome

Dear Participants,

Welcome to the 4th International Scientific, Medical and Family Conference on Barth syndrome! With a nod to the railroad origins of the first owner and builder of this historic hotel, our theme is *"On Track Toward a Cure"* and we hope that this Conference will indeed confirm our direction and accelerate our speed to that cure.

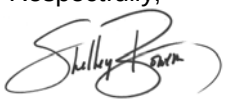
This Conference continues to be unique among rare disorders in that it brings affected families and individuals, research scientists and clinicians together in one place at one time. The Barth Syndrome Foundation and our affiliates in Canada, South Africa and the UK firmly believe that while each of these groups can make some progress alone in their individual efforts, together, we are so much more powerful.

Doctors who might see a single Barth patient in a lifetime will have the opportunity to see 40 at once and gain a greater understanding of the science underlying potential new treatments. Scientists will have the chance to hear how patients are faring under various treatments, how Barth syndrome affects a boy's life and be invited to use their considerable imagination to create hypotheses about the possible connections between the symptoms and their underlying causes… which can then form the basis for future research. And the families have a unique opportunity to be seen by the world's greatest experts in Barth syndrome and contribute directly to the search for a cure by providing their information, their histories and even their own tissue to the search for a cure.

Nor are the emotional benefits of gathering together to reinforce our commitment to making the world a better, more friendly place for our children and our grandchildren to be overlooked! We all have made a great effort to come to Clearwater, Florida in July. Many others are unable to come but wish that they were here with us. Above all, we consider everyone here to be a part of the greater Barth Family. We have built a high level of trust in each other over the years, and we are certainly depending on each other. And if past Conferences are any measure, we also know that we have a lot of fun together too!

So please make the most out of your time here. Reach out to say 'hello' to someone you don't know and listen to their story and questions. Share your own experience and questions. Be open and let's find new ways to work together to help each other stay on track toward a cure for Barth syndrome. We are certainly all on board this train together! I hope you all enjoy the Conference.

Respectfully,



Valerie ('Shelley') Bowen
President

Varner Award for Pioneers in Science and Medicine

In memory of Paula and Woody Varner, the Board of Directors of the Barth Syndrome Foundation has created the Varner Award for Pioneers in Science and Medicine, to be presented for the first time at our biennial 2008 Scientific, Medical and Family Conference. This award is to be given to a scientist or physician whose dedication to work in his or her field has made a positive and lasting impact on Barth syndrome. The award will be funded from the Paula and Woody Varner Science and Medicine Fund.

Monday, July 21, 2008

Welcome Reception *(Candlelight Ballroom)*

7:00—10:00 pm

Meet new families, enjoy a slide show, receive welcome packets and information about clinics, meetings and sign the kids up for fun activities, including boat tours, the zoo, BounceU and more! *(Light snacks available)*

Kids' Night at the Movies *(Starlight Ballroom)*

7:00—10:00 pm

Ages 11 & under enjoy a movie and snacks under the stars! Children under the age of three must be accompanied by an adult/guardian during Monday's Movie Night.

Ghost Tour (*Starlight Ballroom Foyer)*

7:00—10:00 pm

Ages 12 & up embark on a ghost tour to the 'off-limits area" of the hotel where phantom voices are heard, lights turn themselves on and off, doors open and close themselves, phantom faces appear in the windows. A disconnected phone in the unused 4th floor may ring.

Tuesday & Wednesday, July 22-23, 2008

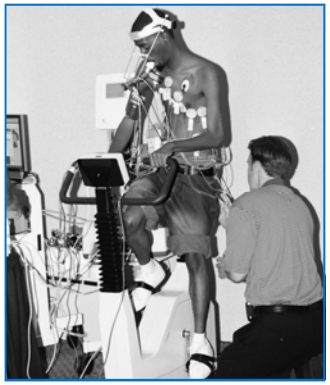
Tuesday, 8:00—6:00 / Wednesday, 8:00—5:00

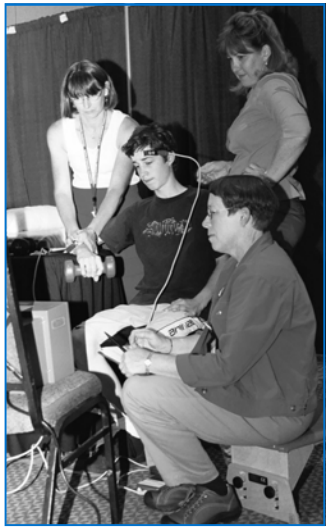
Barth Syndrome Clinics *(Tiffany Ballroom)*

Two days of Barth clinics where families and clinicians share and learn valuable information about the clinical aspects of Barth syndrome. This exchange between families and clinicians about the many nuances of Barth syndrome gives rise to opportunities to explore new ideas and discuss issues of common theme. Data collected as a result of these clinics will feed the Barth Syndrome Registry to further the understanding of this disorder. The BSF clinics have been hailed as a model approach by other health advocacy groups. *(Arts, crafts, movies, outdoor games and Wii activities for all)*

Cardiology Clinics

Carolyn T. Spencer, MD
Barry J. Byrne, MD, PhD
Sharonda Aikens
Petar Breitinger, PA
Randall M. Bryant, MD
Todd Cade, PT, PhD
Vicki Hay, ECHO Technician
Jessica Lohmann, ECHO Technician
Melissa Maisenbacher, MS, CGC
Renee Margossian, MD
Sharon Redfearn, ARNP
Terry Sexton, ARNP
Renata Shih, MD
Dianne Stanford, RN





Cardiology Strength Test

Jane Day, PhD, PT
Jodi Lowe, DHSc, PT

Education

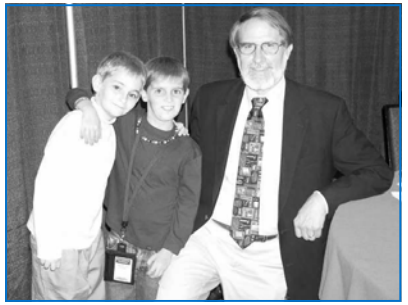
Eileen Q. Juico, MA, MEd
Jonathan Rosenshine, MA, MEd

Genetics

Rebecca L. Kern, MGC
Iris L. Gonzalez, PhD

Metabolism

Richard I. Kelley, MD, PhD



Neurology

Ariel Sherbany, MD, PhD

Nutrition

Rhonda Avery, RD, LD/N, CDE
Carrie Crain, BS
Linda Croxton, MSN, ARNP, CDE
Penny Porch Edwards, MS, RD, LD/N

Physical & Occupational Therapy

Karin Colby Watson, MPT
Jeanette VanDuyne, PT, PCS
Bobbie King, OTR/L

Social Events

Tuesday, July 22, 2008
Thursday, July 24, 2008

Golf—Belleview Biltmore Gulf Club

4:00 pm—*till dark*

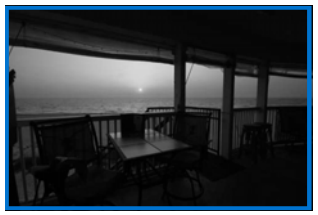
Enjoy a round of golf at the Biltmore Golf Club (reduced rates of $20 includes green fees, cart and clubs). Food is available at the Clubhouse Grill.

Tuesday, July 22, 2008

Lowry Park Zoo

2:00pm—*till close*

Visit the #1 family zoo in America and see more than 1,800 animals and relax in the 56 acres of lush natural habitats. Passes are complimentary!



Wednesday, July 23, 2008

6:00—10:00 pm — Beach House Luau *(Belleview Beach Club)*

Board the shuttle to the Sunset Cabana and enjoy swimming, walking on the beach and a beautiful sunset during our private beach party. *(Shuttle services will begin at 5:30 and run continuously as needed.)*

Thursday, July 24, 2008

7:00—10:00 pm — Clearwater Threshers vs. Ft. Myers Miracle Baseball Game

(Bright House Field, 601 North Old Coachman Road, Clearwater, FL)

Cheer for the local team! Tickets are complimentary.

Friday, July 25, 2008

SOCIAL EVENT FOR ALL — *The Roaring Twenties*

17:30—18:30 — Speakeasy & Prohibition Tour *(St. Andrew's Pub)*

18:30—23:00 — Dinner & Entertainment *(Starlight Ballroom)*

An evening of fun and socialization for ALL conference participants! This casual event brings together our families, clinicians, physicians, scientists, volunteers and those who have an interest in Barth syndrome. We will all participate in the Prohibition Tour given by the hotel at the beginning of the evening, in conjunction with happy hour. The tour ends back upstairs where we'll proceed to the ballroom for dinner, dancing, etc. Entertainment will be provided by Lucas Productions.

SIMULTANEOUS SESSIONS AT A GLANCE

Scientific & Medical Sessions

Note: All Scientific and Medical Sessions will be held in the Belleair Amphitheater

Thursday, July 24, 2008
7:30—8:30: Breakfast Buffet *(Starlight Ballroom)*

8:30—12:00 — Tafazzin and Cardiolipin

12:00—13:15 — Luncheon Buffet and Varner Award Ceremony *(Starlight Ballroom)*

13:30—17:00 — Population and Functional Screening

17:30—19:30 — Poster Sessions *(Carriage Porch)*

Friday, July 25, 2008
7:30—8:30 — Breakfast Buffet *(Starlight Ballroom)*

8:30—12:00 — Consequences of Tafazzin Dysfunction

12:00—13:15 — Luncheon Buffet *(Carriage Porch)*

13:30—17:00 — Model Systems and Clinical Factors

17:00—17:30 — Ideas for Future Consideration

17:30—23:00 — Dinner and Social Event *(Starlight Ballroom)*

Saturday, July 26, 2008
8:30—12:00 — Scientific & Medical Advisory Board Breakfast and Working Meeting *(Founder's Room)*

Family Sessions

Note: All Family Sessions will take place in the Candlelight Ballroom

Thursday, July 24, 2008
7:30—9:00 — Breakfast Buffet *(Starlight Ballroom)*

9:15—9:40 — Welcome & Session Preview

9:45—11:15 — Cardiac Aspects of BTHS

11:15—11:45 — Overview/Breakout Discussions

12:00—13:15 — Luncheon Buffet and Varner Award Ceremony *(Starlight Ballroom)*

13:30—14:00 — Session Preview

14:00—15:30 — Hematological Aspects of BTHS

15:30—16:00 — Overview/Breakout Discussions

18:30—19:30 — Poster Session *(Carriage Porch)*

Friday, July 25, 2008
7:30—9:00 — Breakfast Buffet *(Starlight Ballroom)*

9:15—9:45 — Session Preview

9:45—11:15 — Risks...Trends...Management

11:15—11:45 — Overview/Breakout Discussions

12:00—13:00 — Luncheon Buffet *(Starlight Ballroom)*

13:15—14:15 — Biochemical Function of Lipids

14:15—16:00 — Report on Research

17:30—23:00 — Dinner and Social Event for All *(Starlight Ballroom)*

Saturday, July 26, 2008
7:30—9:00 — Breakfast Buffet *(Starlight Ballroom)*

9:15—9:45 — Icebreaker/Session Preview

9:45—10:30 — Neuromuscular Aspects of BTHS

10:30—11:15 — Day-to-Day Issues

11:15—11:45 — Overview/Breakout Discussions

12:00—13:00 — Luncheon Buffet *(Starlight Ballroom)*

13:15—15:45 — Family Breakout Sessions

⇒ *Birth—5 years (Candlelight Ballroom)*

⇒ *6—11 (Candlelight Foyer)*

⇒ *12—16 (Committee Room)*

⇒ *17—adult (Henry's Library)*

16:15—17:00 — Finale

Affected Individual Sessions

Note: All Affected Individual Sessions will take place in the Hibiscus Room

Thursday, July 24, 2008
7:30—9:00 — Breakfast Buffet *(Starlight Ballroom)*

9:00 — Ice Breaker

8:30—11:30 — Offsite Excursion (Clearwater Marine Aquarium Eco Boat Cruise) or Swimming pool, Wii, Teen Club, Monster Sports

12:00—13:15 — Luncheon Buffet

13:30—14:15 — Bullying *(Ages 9-14)*
13:30—14:15—Time w/ Dr. Richard I. Kelley *(Ages 15+)*

14:15—15:00 — Projects (Slide Show)

15:00—16:00 Hang Time *(Swimming pool, Teen Club, Wii, Guitar Hero, Monster Sports)*

Friday, July 25, 2008
7:30—9:00 — Breakfast Buffet *(Starlight Ballroom)*

9:00—Ice Breaker

9:10—11:30 — Offsite Excursion (BounceU) or Swimming pool, Wii, Teen Club, Monster Sports

12:00—13:00 — Luncheon Buffet

13:30—14:30 — NASA Astronaut Andy Allen

14:30—15:15 — Fun with Genetics *(Ages 9—14)*
14:30—15:15 — Transitions *(Ages 15+)*

15:15—16:00 — Hang Time (*Swimming, Teen Club, Wii, Guitar Hero, Monster Sports)* or Projects (Slide Show)

17:30—23:00 — Prohibition Tour / Dinner & Social Event for All *(Starlight Ballroom)*

Saturday, July 26, 2008
7:30—9:00 — Breakfast Buffet *(Starlight Ballroom)*
9:00—10:30 — Ice Breaker

10:30—11:15—Family Meeting *(Candlelight Ballroom)* or
10:30—12:00 — Hang Time *(Swimming, Teen Club, Wii, Guitar Hero, Monster Games)*

12:00—13:00 — Luncheon Buffet *(Starlight Ballroom)*

13:15—14:00 — How Do I Explain Barth Syndrome *(All Ages)*

14:00—15:00 — Hang Time *(Ages 9—14)*
14:00—15:00 — Adult Matters *(Ages 15+)*

15:00—16:00 — Finalize Slide show

16:15—17:00 — Finale

Sibling Sessions

Note: All Sibling Sessions will take place in the Magnolia Room

Thursday, July 24, 2008
7:30—9:00 — Breakfast Buffet *(Starlight Ballroom)*

9:00 — Ice Breaker

9:15—11:30 — Offsite Excursion (Clearwater Marine Aquarium Eco Boat Cruise) or Swimming pool, Wii, Teen Club, Monster Sports

12:00—13:15 — Luncheon Buffet

13:30—14:15 — Fun with Genetics

14:15—15:00 — Projects *(Slide Show)*

15:00—16:00 — Hang Time *(Swimming pool, Teen Club, Wii, Guitar Hero, Monster Sports)*

Friday, July 25, 2008
7:30—9:00 — Breakfast Buffet *(Starlight Ballroom)*

9:00—Ice Breaker

9:15—11:30 — Offsite Excursion (BounceU) or Swimming pool, Wii, Teen Club, Monster Sports

12:00—13:00—Luncheon Buffet

13:00—14:30 — NASA Astronaut Andy Allen

14:30—15:15 — How Do I Explain Barth Syndrome

15:15—16:00 — Hang Time *(Swimming, Teen Club, Wii, Guitar Hero, Monster Games)*

17:30—23:00 — Prohibition Tour / Dinner and Social Event for All *(Starlight Ballroom)*

Saturday, July 26, 2008
7:30—9:00 — Breakfast Buffet *(Starlight Ballroom)*

9:00—10:30 — Ice Breaker

10:30—11:15 — Family Meeting *(Candlelight Ballroom)* or
10:30—12:00 — Hang Time *(Swimming, Teen Club, Wii, Guitar Hero, Monster Games)*

12:00—13:00 — Luncheon Buffet *(Starlight Ballroom)*

13:15—14:00 — Time w/ Lauren Stutts

14:00—15:00 — Hang Time *(Swimming, Teen Club, Wii, Guitar Hero, Monster Games)*

15:00—16:00 — Finalize Slide Show

16:15—17:00 — Finale

SCIENTIFIC AND MEDICAL SESSIONS

Thursday, July 24, 2008

7:30—8:30 **BREAKFAST BUFFET** *(Starlight Ballroom)*

Note: All Scientific & Medical Sessions will be held in the Belleair Amphitheater

8:30—12:00 **TAFAZZIN AND CARDIOLIPIN**
Grant M. Hatch, PhD—Chairman

Function of tafazzin isoforms
Michael Schlame, MD

Cardiolipin's (CL's) pK2's suggest a role for CL in ATP synthesis
Thomas Haines, PhD

Tafazzin, cardiolipin and mitochondria structure
Devrim Acehan, PhD

Break~10:00

Clinical aspects of a Barth syndrome patient with exon-5 mutation
Michael Carboni, MD

Characterizing tafazzin and Barth syndrome mutant tafazzins
Steven M. Claypool, PA, PhD

Alterations in the cardiolipin profile leading to heart failure in a rat model and its restoration with diet
Genevieve Sparagna, PhD

12:00—13:15 **LUNCHEON BUFFET FOR ALL** *(Starlight Ballroom)*
Presentation of Varner Award for Pioneers in Science and Medicine

13:30—17:00 **POPULATION AND FUNCTIONAL SCREENING**
Ronald J.A. Wanders, PhD—Chairman

***Will McCurdy—BTHS individual introduction**

Foetal hydrops, cardiomyopathy, and death due to Barth syndrome
Colin G. Steward, FRCP, FRCPCH, PhD

Rapid biochemical detection of BTHS using HPLC-tandem mass spectrometry
Willem Kulik, PhD

What can we learn from mRNA analysis when *TAZ* mutation detection is negative?
Susan Kirwin

Break~15:00

The power of patient registries for rare diseases
Steven E. Lipschultz, MD

Cardiolipin provides an essential activating platform for Caspase-8 on mitochondria
Eyal Gottlieb, PhD

Neutropenia in Barth syndrome
Andrew Aprikyan, PhD

17:30—19:30 **POSTER SESSION** *(Carriage Porch)*
With authors and open discussions
(Wine and cheese served)

For a complete listing of authors and titles please see page 10.

SCIENTIFIC AND MEDICAL SESSIONS

Friday, July 25, 2008

7:30—8:30 **BREAKFAST BUFFET** *(Starlight Ballroom)*

Note: All Scientific & Medical Sessions will be held in the Belleair Amphitheater

8:30—12:00 **CONSEQUENCES OF TAFAZZIN DYSFUNCTION**
Todd Cade, PT, PhD—Chairman

***Robert Hope—BTHS individual introduction**

Cardiomyopathy, skeletal myopathy and functional capacity in Barth syndrome
Carolyn T. Spencer, MD

Break~10:00

Arrhythmias in Barth syndrome: Where do we go from here?
Randall M. Bryant, MD

What is the matter with the cardiolipin molecular species?
Xianlin Han, PhD

A Barth-like disorder caused by a defect in mitochondrial protein import
Robert E. Jensen, PhD

Hypocholesterolemia in BTHS lymphoblasts
Kristin Hauff, BSc

Genetic suppressors of *TAZ* mutant phenotype in Drosophila—potential targets for therapy of Barth syndrome
Mindong Ren, PhD

12:00—13:15 **LUNCHEON BUFFET** *(Carriage Porch)*
for Scientific and Medical Community

13:30—17:00 **MODEL SYSTEMS AND CLINICAL FACTORS**
Richard I. Kelley, MD, PhD—Chairman

***Michael Bowen—BTHS individual introduction**

Perturbation of the osmotic stress response in cardiolipin deficient mutants
Miriam L. Greenberg, PhD

Proteomic analysis of the consequences of tafazzin-deficiency in *S. cerevisiae*
Frederic M. Vaz, PhD

Cardiac aspects of Barth syndrome: UK experience
Break~15:00 *Beverly Tsai-Goodman, BM, MRCP, MD*

Psychosocial aspects of Barth syndrome
Marni L. Jacob, BS

Measurement of whole-body nutrient metabolism in Barth syndrome: What can this tell us?
Todd Cade, PT, PhD

17:00—17:30 **IDEAS FOR FUTURE CONSIDERATION**
(Chairmen wrap-up of Scientific and Medical Sessions)

17:30—18:30 **SPEAKEASY AND PROHIBITION TOUR**
(St. Andrews Pub)

18:30—23:00 **DINNER AND SOCIAL EVENT FOR ALL**
(Starlight Ballroom)

SCIENTIFIC AND MEDICAL SESSION

Saturday, July 26, 2008

8:30—12:00 **Scientific & Medical Advisory Board Breakfast and Working Meeting** *(Founder's Room)*

(Scientific & Medical Advisory Board members and invited guests)

- ⇒ **Off-year meeting focus and location**
- ⇒ **Treatment guidelines**
- ⇒ **Tafazzin knockdown mouse update**
- ⇒ **Update on antibody to human tafazzin**
- ⇒ **Barth Syndrome Registry and DNA Bank hypotheses generation**

Dr. Richard I. Kelley presenting at BSF's 2006 conference.

Dr. Barry J. Byrne presenting at BSF's 2006 conference.

Barth Syndrome Foundation of Canada

The Barth Syndrome Foundation of Canada
is the proud sponsor of the 2008 Poster Session

Poster Session *(Title/Author)*

Psychosocial functioning in youth with Barth syndrome
Marni L. Jacob, BS, Department of Psychology, University of Georgia, Athens, GA, USA

Mining the *TAZ* Mutations Database
Iris L. Gonzalez, PhD, A.I. duPont Hospital for Children, Visiting Research Scientist, Wilmington, DE, USA

Proteomic analysis of Barth syndrome cells
Riekelt H. Houtkooper, MSc, Laboratory Genetic Metabolic Diseases, Academic Medical Center, Amsterdam, The Netherlands

Cardiolipin and monolyso-cardiolipin analysis in fibroblasts, lymphocytes and tissue using HPLC-mass spectrometry as a diagnostic test for Barth syndrome
Riekelt H. Houtkooper, MSc, Laboratory Genetic Metabolic Diseases, Academic Medical Center, Amsterdam, The Netherlands

Loss of cardiolipin leads to longevity defects that are alleviated by down-regulation of the HOG stress response pathway
Jingming Zhou, PhD Student, Department of Biological Sciences, Wayne State University, Detroit, MI, USA

Dysmorphology of Barth syndrome
Rob Hastings, MD, Department of Clinical Genetics, St. Michael's Hospital, Bristol, UK

10*N*-Nonyl acridine orange inhibits cardiolipin polymorphism and mimics Barth syndrome phenotype
Toshihide Kobayashi, PhD, Lipid Biology Laboratory, RIKEN, Wako, Saitama, Japan

The transacylation space of tafazzin: A linear algebra approach to lipidomics data
Michael Schlame, MD, Departments of Anesthesiology and Cell Biology, New York University School of Medicine, New York, NY, USA

Bloodspot assay using HPLC–tandem mass spectrometry for the detection of Barth syndrome
Willem Kulik, PhD, Academic Medical Center, University of Amsterdam, Laboratory Genetic Metabolic Diseases, Department of Clinical Chemistry, Amsterdam, The Netherlands

A Drosophila model to investigate the function of cardiolipin
Ashim Malhotra, PhD, Department of Anesthesiology, New York University School of Medicine, New York, NY, USA

Barth Syndrome Registry and DNA Bank: Initial data report
Melissa Maisenbacher, MS, CGC, Division of Genetics, University of Florida, Gainesville, FL, USA

Identification of physiological factors exacerbating the tafazzin mutation in *S. cerevisiae*
Amit S. Joshi, Graduate Student, Department of Biological Sciences, Wayne State University, Detroit, MI, USA

Elucidating the effects of missense mutations in the taffazin gene: Implications for Barth syndrome
Shali Zhang, Student Research Intern, New York University School of Medicine, New York, NY, USA

Function of tafazzin isoforms from humans and Drosophila
Yang Xu, MD, PhD, Department of Anesthesiology, New York University School of Medicine, New York, NY, USA

Neutropenia in Barth syndrome
Andrew Aprikyan, PhD, Division of Hematology, University of Washington School of Medicine, Seattle, WA, USA

Quantification of motor performance in boys with Barth syndrome
Jane Day, PhD, Physical Therapy, University of Florida, Gainesville, FL, USA

Impaired skeletal muscle oxygen utilization contributes to exercise intolerance in Barth syndrome
Carolyn T. Spencer, MD, Congenital Heart Center, University of Florida, Gainesville, FL; Children's Hospital Boston, Cardiology, Boston, MA, USA

On behalf of the Barth Syndrome Foundation and our international affiliates, we would like to thank all of those dedicated to unraveling the mysteries of Barth syndrome and advancing knowledge about this complex disorder. This includes the scientists who focus their curiosity and expertise on new discoveries and the physicians who dedicate themselves to the treatment of our children. It also includes the affected individuals and their families who are willing to share medical data and biological specimens to facilitate scientific and medical progress for all. Together, we are saving lives through education, advances in treatment and pursuit of a cure. We also would like to thank ALL of the Barth families who contributed photographs for the 2008 Conference Video.

Organizing Committee

Bowen, Valerie (Shelley)
Buddemeyer, Leslie
Kugelmann, Jan

Volunteers

Acehan, Dr. Devrim
Aikens, Sharonda
Aprikyan, Dr. Andrew
Avery, Rhonda, RD, LD/N, CDE
Baffa, Kevin
Bogert, Nick
Bogert, Sally
Bowen, Michael
Bowen, Valerie (Shelley)
Breitinger, Petar, PA
Brody, DW
Brody, Tracy
Bryant, Dr. Randall M.
Buddemeyer, Andrew
Buddemeyer, Leslie
Byrne, Dr. Barry J.
Cade, Dr. Todd
Carboni, Dr. Michael
Christie, Dr. William W.
Claypool, Dr. Steven M.
Crain, Carrie
Croxton, Linda, MSN, ARNP, CDE
Dannels, Terry
Day, Dr. Jane
Drake, Brian
Edwards, Penny Porch, MS, RD, LD/N
Elwood, Lynn
Fairchild, Julie
Floyd, Julie
Galbraith, Lois
Gonzalez, Dr. Iris L.
Gottlieb, Dr. Eyal
Greenberg, Dr. Miriam L.
Haines, Dr. Thomas
Han, Dr. Xianlin
Hare, Craig A. (Paramedic EMS Division Chief)
Hatch, Dr. Grant M.
Hauff, Kristin, BSc
Hay, Vickie
Holly, Keli
Hope, Chris
Hope, Robert
Jacob, Marni L.
Jensen, Dr. Robert E.
Juico, Eileen Q., MA, MEd
Kelley, Dr. Richard I.
Kern, Rebecca L., MGC
King, Bobbie, OT
Kirwin, Susan
Kugelmann, Jan
Kugelmann, Lee
Kugelmann, Steve
Kulik, Dr. Willem
Layton, Alanna
Lipshultz, Dr. Steven E.
Lochner, Joyce
Lohman, Jessica
Lowe, Jodi
Lucas, Kendal (Lucas Productions)
Maisenbacher, Melissa, MS, CGC
Mann, Shelia
Margossian, Dr. Renee
Mazzocco, Dr. Michele
McCurdy, Kate
McCurdy, Will
Miller-Drake, Erin
Monahan, Bill
Moore, Lorna
Moore, Nigel
Morris, Les
Morris, Travis
Olson, Richard
Oson, Sharon
Olson, Brandy
Osnos, Susan
Pagano, Jim
Pagano, MaryLou
Pinellas County EMS / Fire Administration
Randell, Amer
Randell, Jay
Rawlings, Sheila
Redfearn, Sharon, ARNP
Reimschisel, Dr. Tyler
Ren, Dr. Mindong
Rivers, Nina
Rosenshine, Jonathan, MA, Med
Saroyan, Dr. John
Schlame, Dr. Michael
Sedefian, Lynda
Sexton, Terry
Sherbany, Dr. Ariel
Shih, Renata
Sparagna, Dr. Genevieve
Spencer, Dr. Carolyn T.
St. Amant, Jay
Stanford, Dianne
Steward, Dr. Colin G.
Strain, Donna
Stutts, Lauren
Sunstar Emergency Medical Services of Pinellas County, Florida
Telles, Michelle
Toth, Dr. Matthew J.
Tsai-Goodman, Dr. Beverly
VanDuyne, Jeanette, PT
Varner, Judy
Vaz, Dr. Frederic M.
Vogt, Jerre
Wanders, Dr. Ronald J.A.
Watson, Karin, PT
Weltlich, Dodie
Whitney, Scott (Bright Circle Inc.)
Wilkins, John
Wilkins, Mike
Wilkins, Sue
Wilks, Carol

FAMILY SESSIONS

Thursday, July 24, 2008

7:30—9:00 **BREAKFAST BUFFET** *(Starlight Ballroom)*

Note: All Family Sessions will be held in the Candlelight Ballroom

9:15—9:40 **WELCOME AND SESSION PREVIEW**
Shelley Bowen

9:45—11:15 **CARDIAC ASPECTS OF BARTH SYNDROME**
Carolyn T. Spencer, MD—Chairman
Panel: Randall Bryant, MD; Steven Lipshultz, MD

Discussions about cellular function and its impact on the Barth syndrome heart including heart failure, transplant, left ventricle non-compaction and arrhythmia issues.

11:15—11:45 **SESSION OVERVIEW / BREAKOUT DISCUSSIONS**

12:00—13:15 **LUNCHEON BUFFET** *(Starlight Ballroom)*
Presentation of Varner Award for Pioneers in Science & Medicine

13:30—14:00 **SESSION PREVIEW**

14:00—15:30 **HEMATOLOGICAL ASPECTS OF BARTH SYNDROME**
Day-to-day issues and new findings
Colin G. Steward, FRCP, FRCPCH, PhD—Chairman

15:30—16:00 **SESSION OVERVIEW / BREAKOUT DISCUSSIONS**

Note: Poster Session will be extended to families from 18:30—19:30 *(Carriage Porch)*

Childcare *(Tiffany Ballroom)*

Childcare will be provided on Thursday thru Saturday, July 24—26, 2008 from 9:00am—4:00pm.

All children under the age of eight should be registered. It is required that a parent or guardian register their child, and check-in and check-out. No other person will be permitted to do so unless specified on the registration form.

Pre-Registration: Thursday, July 24 beginning at 8:00am *(Tiffany Ballroom Foyer)*

Registration: Friday and Saturday, July 25—26 beginning at 9:00am *(Tiffany Ballroom Foyer)*

AFFECTED INDIVIDUAL SESSIONS

SIBLING SESSIONS

Thursday, July 24, 2008

7:30—9:00 **BREAKFAST BUFFET** *(Starlight Ballroom)*

Note: All Affected Individual Sessions will be held in the Hibiscus Room

7:30—9:00 **BREAKFAST BUFFET** *(Starlight Ballroom)*

Note: All Sibling Sessions will be held in the Magnolia Room

Note: Those participating in Boat Cruise need to arrive by 8:30

8:30—11:30 **OFF-SITE EXCURSION**
Clearwater Marine Aquarium Eco — Boat Cruise *(optional)*
Other Activities: Swimming pool, Wii, Teen Club, Monster Sports

8:30—11:30 **OFF-SITE EXCURSION**
Clearwater Marine Aquarium Eco — Boat Cruise *(optional)*
Other Activities: Swimming pool, Wii, Teen Club, Monster Sports

12:00—13:15 **LUNCHEON BUFFET** *(Starlight Ballroom)*
Presentation of Varner Award for Pioneers in Science & Medicine

12:00—13:15 **LUNCHEON BUFFET** *(Starlight Ballroom)*
Presentation of Varner Award for Pioneers in Science & Medicine

13:30—14:15 **BULLYING** ***(Ages 9—14)***
Lauren Stutts; Jay St. Amant, MS; Marni Jacob

13:30—14:15 **FUN WITH GENETICS**
Rebecca Kern, MGC; Iris L. Gonzalez, PhD

13:30—14:15 **TIME WITH DR. RICHARD I. KELLEY** ***(Ages 15+)***

14:15—15:00 **PROJECTS** **(Slide Show)**

14:15—15:00 **PROJECTS** **(Slide Show)**

15:00—16:00 — HANG TIME ***~ Swimming pool, Teen Club, Wii, Guitar Hero, Monster Sports***

After Session Activities: Golf ~ Threshers Baseball Game ~ Scientific Poster Display

The Barth Syndrome Foundation of Canada
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July 24, 2008 Breakfast Buffet

Barth Syndrome
Foundation of Canada

FAMILY SESSIONS

Friday, July 25, 2008

7:30—9:00 **BREAKFAST BUFFET** *(Starlight Ballroom)*

Note: All Family Sessions will be held in the Candlelight Ballroom

9:15—9:45 **SESSION PREVIEW**

9:45—11:15 **RISKS...TRENDS...MANAGEMENT...**
On Track Toward a Cure
Richard I. Kelley, MD, PhD—Chairman
Melissa Maisenbacher, MS, CGC; Rebecca Kern, MGC;

11:15—11:45 **SESSION OVERVIEW/BREAKOUT DISCUSSIONS**

12:00—13:00 **LUNCHEON BUFFET** *(Starlight Ballroom)*

13:15—14:15 **BIOCHEMICAL FUNCTION OF LIPIDS**
A layman's guide to lipids and how they are related to Barth syndrome
William W. Christie, MBE, BSc, PhD, DSc, FRSE

14:15—16:00 **REPORT ON RESEARCH**
Summary of BSF funded research
Matthew J. Toth, PhD—Chairman
BSF Grant Recipients

17:30—18:30 **SPEAKEASY & PROHIBITION TOUR** *(St. Andrew's Pub)*

18:30—23:00 **DINNER & SOCIAL EVENT FOR ALL**
(Starlight Ballroom)
The Roaring Twenties—*Dinner and Entertainment for ALL. Entertainment provided by Kendal Lucas of Lucas Productions.*

AFFECTED INDIVIDUAL SESSIONS

SIBLING SESSIONS

Friday, July 25, 2008

	AFFECTED INDIVIDUAL SESSIONS	SIBLING SESSIONS
7:30—9:00	**BREAKFAST BUFFET** *(Starlight Ballroom)* ***Note: All Affected Individual Sessions will be held in the Hibiscus Room***	**BREAKFAST BUFFET** *(Starlight Ballroom)* ***Note: All Sibling Sessions will be held in the Magnolia Room***
9:00	**ICE BREAKER**	**ICE BREAKER**
9:00—11:30	**OFF-SITE EXCURSIONS** **BounceU** *(optional)* *Other Activities: Swimming pool, Wii, Teen Club, Monster Sports*	**OFF-SITE EXCURSIONS** **BounceU** *(optional)* *Other Activities: Swimming pool, Wii, Teen Club, Monster Sports*
12:00—13:00	**LUNCHEON BUFFET** *(Starlight Ballroom)*	**LUNCHEON BUFFET** *(Starlight Ballroom)*
13:30—14:30	**NASA ASTRONAUT ANDREW M. ALLEN** Lieutenant Colonel, USMC, Ret. *(Selected by NASA in 1987, Allen is a veteran of three space shuttle flights.)*	**NASA ASTRONAUT ANDREW M. ALLEN** Lieutenant Colonel, USMC, Ret. *(Selected by NASA in 1987, Allen is a veteran of three space shuttle flights.)*
14:30—15:15	**FUN WITH GENETICS *(Ages 9—14)*** *Rebecca Kern, MGC; Iris L. Gonzalez, PhD*	**HOW DO I EXPLAIN BARTH SYNDROME** *Jay St. Amant, MS; Marni Jacob*
14:30—15:15	**TRANSITIONS *(Ages 15+)*** *Lauren Stutts*	

15:15—16:00 — HANG TIME ~ *Swimming pool, Teen Club, Wii, Guitar Hero, Monster Sports Or Projects/Slide Show*

17:30—23:00 — PROHIBITION TOUR AND SOCIAL EVENT FOR ALL *(Starlight Ballroom)*

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July 25, 2008 Breakfast Buffet

FAMILY SESSIONS

Saturday, July 26, 2008

7:30—9:00 **BREAKFAST BUFFET** *(Starlight Ballroom)*

Note: All Family Sessions will be held in the Candlelight Ballroom

9:15—9:45 **SESSION PREVIEW** *(Candlelight Ballroom)*

9:45—10:30 **NEUROMUSCULAR ASPECTS OF BARTH SYNDROME**
Interventional Issues/Exercise Physiology
Todd Cade, PT, PhD—Chairman

Discussions about hypersensitivities, pain, fatigue and exercise intolerance, including therapies and devices to improve stamina.

10:30—11:45 **DAY-TO-DAY ISSUES**
Marni L. Jacob, BS; Jay St. Amant, MS; Lauren Stutts

Perspectives from affected individuals and siblings
Kevin Baffa; Andrew Buddemeyer; Robert Hope; Will McCurdy; John Wilkins / James Baffa; Ben Buddemeyer; Lee Kugelmann; Alanna Layton

12:00—13:00 **LUNCHEON BUFFET** *(Starlight Ballroom)*

13:15—15:45 **FAMILY BREAKOUT SESSIONS**
Age appropriate sessions to discuss issues relating to your child

⇒ ***Birth—5 years*** *(Candlelight Ballroom)*

⇒ ***6—11 years*** *(Candlelight Foyer)*

⇒ ***12—16 years*** *(Committee Room)*

⇒ ***17—adult*** *(Henry's Library)*

16:15—17:00 **FINALE WITH FAMILIES AND CHILDREN**
(Tiffany Ballroom)

AFFECTED INDIVIDUAL SESSIONS SIBLING SESSIONS

Saturday, July 26, 2008

7:30—9:00 **BREAKFAST BUFFET** *(Starlight Ballroom)*

Note: All Affected Individual Sessions will be held in the Hibiscus Room

9:00—10:30 **ICE BREAKER**
Projects (Slide Show)

7:30—9:00 **BREAKFAST BUFFET** *(Starlight Ballroom)*

Note: All Sibling Sessions will be held in the Magnolia Room

9:00—10:30 **ICE BREAKER**
Projects (Slide Show)

10:30—11:15—FAMILY MEETING: PERSPECTIVES FROM AFFECTED INDIVIDUALS AND SIBLINGS
Chairs: Lauren Stutts; Jay St. Amant, MS; Marni Jacobs
Speakers: Kevin Baffa, Andrew Buddemeyer, Robert Hope, Will McCurdy, John Wilkins
James Baffa, Ben Buddemeyer, Lee Kugelmann, Alanna Layton
OR
10:30—12:00* HANG TIME ~ *Swimming pool, Teen Club, Wii, Guitar Hero, Monster Sports

12:00—13:00 **LUNCHEON BUFFET** *(Starlight Ballroom)*

13:15—14:00 **HOW DO I EXPLAIN BARTH SYNDROME *(All Ages)***
Jay St. Amant, MS; Marni Jacobs

14:00—15:00 **HANG TIME (Slide Show) *(Ages 9—14)***

14:30—15:00 **ADULT MATTERS *(Ages 15+)***
Randall M. Bryant, MD

12:00—13:00 **LUNCHEON BUFFET** *(Starlight Ballroom)*

13:15—14:00 **TIME WITH LAUREN STUTTS**

14:00—15:00 **HANG TIME (Slide Show)**

15:00—16:00 — FINALIZE SLIDE SHOW

16:15—17:00 FINALE WITH FAMILIES AND CHILDREN *(Tiffany Ballroom)*

LATE BREAKING NEWS

Barth Syndrome Foundation Completes Search for Executive Director — Linda Stundis enthusiastically accepts and will attend July 2008 Conference

On behalf of the Barth Syndrome Foundation, Inc. (BSF) Board of Directors, Shelley Bowen (President) and Steve McCurdy (Board Chairman) are very pleased to announce that BSF has hired Linda Stundis as its first Executive Director.

Shelley Bowen requested that BSF add an executive director to our leadership team in order to accelerate BSF's drive toward our vision. The ideal candidate would have the skills and leadership abilities to complement Shelley's strengths and to contribute to the organization's continued growth and progress. At the same time, this individual would respect and preserve the trust and relationships that tie our families, physicians, scientists, volunteers and donors together and have been at the core of our success.

In Linda Stundis, we have found just such a person. She is a strong but quiet leader who offers an excellent fit with BSF at this stage of our development. She is bright and has a great ability to listen, organize and build effective teams. In addition, she has a real passion for helping children and young people. She fully appreciates the opportunity to build upon the hard work that has brought us this far and the great potential to make a real difference. "This is the most exciting position I have ever held," said Linda upon accepting BSF's offer. Shelley Bowen added, "We are absolutely delighted that Linda has agreed to join us, I am looking forward to working in close partnership with her."

Linda will work out of her home in Chestnut Hill, MA where she lives with her son Eric, now 13. She will assume her new position on July 14, 2008 and is looking forward to joining us at the BSF International Scientific, Medical and Family Conference in Clearwater, Florida from July 21-26. "I have so many people to meet and so many things to learn, I can't wait to get started." Please join us in welcoming Linda into our "family".

Photography

Amanda Clark has always had a passion for photography; a gift given to her by a true love, instilled in her a love for others. To repay this blessing, she gives you, and everyone she photographs, a moment in time, warmth and an emotion that she sees through the lens. These feelings touch her heart and are captured to be yours to cherish for a lifetime.

Amanda Clark Portrait Artist
AMANDA CLARK PORTRAIT ARTIST

Barth Syndrome Foundation, Inc.

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The Wilkins Family
is the proud sponsor
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July 24, 2008
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Devrim Acehan, PhD — Postdoctoral Research Associate, New York University School of Medicine, New York, NY, USA

Dr. Acehan's research focuses on structure function relations of biological complexes in isolation and within the context of the cell. During the last five years, Dr. Acehan has been working on the structures of cell-cell junctions in keratinocyte cultures. Recently, Dr. Acehan started a new structural project to study mitochondria in Barth syndrome and related model systems. In particular, he is interested in correlation between cardiolipin deficiency and mitochondria structure in various cell types. To this end he is working with tafazzin knock-out and cardiolipin synthase mutations in fruit flies and mouse embryo stem cells differentiating into cardiomyocytes.

Presentation: Tafazzin, cardiolipin and mitochondria structure *(Scientific & Medical Session)*

Andrew Aprikyan, PhD — Research Assistant Professor of Medicine, Division of Hematology, University of Washington School of Medicine, Department of Medicine, Seattle, WA, USA

Dr. Aprikyan's research focuses on (1) the molecular mechanisms and novel therapies for inherited disorders associated with severe neutropenia and leukemia; (2) mutations in receptors and intracellular proteins (structure-to-function relationships); (3) cancer biology—cellular and animal models of severe leukopenia and leukemia; apoptosis, cell cycle; and bone marrow failure disorders.

Dr. Aprikyan was awarded his PhD in Molecular Biology at the Institute of Molecular Biology, Academy of Sciences, Moscow, Russia (1988). He was Senior Scientist, Department of Molecular Biology of Aging, NASA, Institute of Biochemistry, Yerevan, Armenia (1990-1993); He was Senior Fellow, Division of Oncology, Department of Medicine, University of Washington, Seattle, WA (1993-1997), and in 1998, Senior Fellow, Division of General Internal Medicine, Department of Medicine, University of Washington, Seattle, WA.

Presentation: Neutropenia in Barth syndrome *(Scientific & Medical Session)*

Randall M. Bryant, MD — Director, Interventional Electrophysiology and Pacing: Assistant Professor of Pediatrics, Division of Pediatric Cardiology, University of Florida-Jacksonville/Gainesville; Co-Director, North Florida Children's Comprehensive Cardiac Network, Children's Medical Services, University of Florida-Jacksonville; Director, Transtelephonic Arrhythmia Monitoring Program, Department of Pediatrics, Division of Pediatric Cardiology, University of Florida-Jacksonville/Gainesville, Jacksonville, FL, USA

Dr. Bryant's specialties include pediatric cardiology and pediatric medicine, and focuses on studies which include the use of pacemakers and implantable cardioverter defibrillators in children with hypertrophic cardiomyopathy; natural history and treatment of sinus node dysfunction in pediatric heart transplantation; pacemaker implantation in children with hypertrophic cardiomyopathy.

Presentation: Arrhythmias in Barth syndrome: Where do we go from here? *(Scientific & Medical Session)*
Presentation: Adult Matters *(Affected Individual Session)*

Barry J. Byrne, MD, PhD — Professor, Departments of Pediatrics and Molecular Genetics and Microbiology; Director, Powell Gene Therapy Center; Associate Director, Congenital Heart Center, University of Florida, College of Medicine, Gainesville, FL, USA; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc. Perry, FL; Co-Principal Investigator, Barth Syndrome Registry & DNA Bank, Gainesville, FL, USA

Dr. Byrne is a pediatric cardiologist in the College of Medicine, University of Florida and holds joint appointments of Professor in the Departments of Pediatrics and Molecular Genetics and Microbiology, as well as the Director of the Powell Gene Therapy Center. His laboratory is engaged in a comprehensive research effort in molecular cardiology with emphasis on the diagnosis and treatment of heart failure in infants and children. The program is aimed at genetic therapy for treatment of inherited and acquired cardiovascular disease. As a model system, they are focusing on a fatal form of heart failure due to glycogen storage disease. These programs are being supported by the American Heart Association, Muscular Dystrophy Association and the National Institutes of Health (NHLBI, NIDDK, and NCRR).

Todd Cade, PT, PhD — Assistant Professor of Physical Therapy and Internal Medicine, Washington University School of Medicine, St. Louis, MI, USA

Dr. Cade's research interests include mechanisms and treatments for whole-body and myocardial nutrient metabolism abnormalities in metabolic diseases such as HIV-associated metabolic syndrome, diabetes, and Barth syndrome and in normal and pathologic pregnancy. He currently holds a NIH funded Career Development Award from the National Institute of Diabetes and Digestive and Kidney Diseases and serves as a consultant of a Barth Syndrome Foundation grant entitled, "Cardiac and Skeletal Muscle in Barth Syndrome: Evaluation of Functional Capacity and Energy Metabolism".

Dr. Cade holds a BSc in Kinesiological Science from the University of Maryland, an MSc in Physical Therapy from the University of Miami, Florida and a PhD in Rehabilitation Science/Applied Physiology from the University of Maryland. He is a licensed physical therapist in the State of Missouri.

Chairman—Consequences of Tafazzin Dysfunction *(Scientific & Medical Session)*
Presentation: Measurement of whole-body nutrient metabolism in Barth syndrome—what can this tell us?

Michael Carboni, MD — Assistant Professor in Pediatric Cardiology, Duke Children's Hospital, Durham, NC, USA

Dr. Carboni is an electrophysiologist and medical director of the Pediatric Heart Transplant Service. His clinical interests center on the evaluation and management of cardiomyopathies and heart failure, care of the patient undergoing heart transplantation, and evaluation and treatment of heart rhythm abnormalities. His previous research has involved the clinical and basic science study of inherited arrhythmias such as the long QT syndrome. Currently, his research interests lie in the areas of heart transplantation and its complications, causes of and treatments for cardiomyopathies, and use of biventricular pacemakers in the treatment of heart failure and ventricular dysfunction.

He is a member of multiple societies including the American Heart Association, International Society for Heart and Lung Transplantation, International Pediatric Transplant Association, Heart Rhythm Society, and the Pediatric and Congenital Electrophysiology Society.

Presentation: Clinical aspects of a Barth syndrome patient with exon-5 mutation (*Scientific & Medical Session)*

William W. Christie, MBE, BSc, PhD, DSc, FRSE — Head, Chemistry Department, The Scottish Crop Research Institute *(retired)*; Consultant, Mylnefield Lipid Analysis, Dundee, Scotland

Dr. Christie was Head of the Chemistry Dept, the Scottish Crop Research Institute. Previously he was Head of the Department of Biological Chemistry, Hannah Research Institute in Ayr, Scotland. Throughout his career, Dr. Christie has been involved at the interface between the chemistry and biochemistry of lipids with a special interest in analytical methodology.

Dr. Christie holds an honours BSc in chemistry and a PhD in lipid chemistry from the University of St. Andrews in Scotland. Foremost among Dr. Christie's honours, is the MBE (Member of the Order of the British Empire) appointed by the Queen, election to the Royal Society of Edinburgh, and the Dutton and Bailey Awards of the American Oil Chemists' Society.

Presentation: A Layman's Guide to Lipids *(Family Session)*

Steven M. Claypool, MA, PhD — Postdoctoral Fellow, Department of Chemistry and Biochemistry, University of California at Los Angeles, Los Angeles, CA, USA

Dr. Claypool is a post-doctoral fellow in the Department of Chemistry and Biochemistry at the University of California, Los Angeles. His interests are in understanding the interplay of phospholipids and membrane proteins as determinants of physiology and pathophysiology. Dr. Claypool has initiated a new project for Carla Koehler's mitochondrial biogenesis laboratory in characterizing tafazzin, the protein product of the gene mutated in patients with Barth syndrome, using the yeast, Saccharomyces cerevisiae as the model system.

Dr. Claypool holds a BA in Biological Sciences and a MA in Molecular, Cellular, and Developmental Biology, from the University of California, Santa Barbara. He has a PhD in Immunology from Harvard University, For his thesis, working in the laboratory of Dr. Richard S. Blumberg, he studied the neonatal Fc receptor, FcRn, as expressed in polarized epithelial cells that model the human intestine.

Presentation: Characterizing tafazzin and Barth syndrome mutant tafazzins *(Scientific & Medical Session)*

Iris L. Gonzalez, PhD — Molecular Diagnostics Laboratory, Alfred I. DuPont Hospital for Children, Wilmington, DE *(retired)*; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc., Perry, FL, USA

Dr. Gonzalez, as a molecular geneticist in a diagnostic lab, has performed the genetic test for many patients to confirm a diagnosis of Barth syndrome. In addition, her scientific interests have led her to conduct research (with a BSF grant) on the mRNA associated with Barth syndrome. She also is known by Barth families for writing a layman's guide to genetics that has been extremely valuable to BSF families and others.

Presentation: Fun with Genetics *(Affected Individual & Sibling Sessions)*

Eyal Gottlieb, PhD — Reader, University of Glasgow, Glasgow, UK; Research Group Leader, Cancer Research UK, The Beatson Institute for Cancer Research, Glasgow, UK

Dr. Gottlieb is a group leader at the Beatson Institute for Cancer Research in Glasgow, Scotland. He received his PhD in 1999 from the Weizmann Institute of Science, Israel, where he worked in the laboratory of Moshe Oren on p53 and apoptosis. He carried out his postdoctoral studies with Craig Thompson, first at the University of Chicago as an EMBO Fellow and later at the University of Pennsylvania as a Leukemia and Lymphoma Society Special Fellow. During these studies, he focused on the functions of the BCL2 family of proteins and how they regulate mitochondrial physiology and apoptosis. In 2003, he moved to Scotland to lead the Apoptosis and Tumour Physiology Laboratory at the Beatson Institute.

Presentation: Cardiolipin provides an essential activating platform for Caspase-8 on mitochondria
(Scientific & Medical Session)

Miriam L. Greenberg, PhD — Associate Dean for Research, College of Liberal Arts and Sciences, Professor, Biological Sciences, Wayne State University, Detroit, MI; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc., Perry, FL, USA

Dr. Greenberg is a Professor of Biological Sciences and the Associate Dean for Research in the College of Arts and Sciences at Wayne State University in Detroit, MI. Her laboratory focuses on phospholipid metabolism in yeast as a model to address questions of fundamental importance to human health. One project in her laboratory is to understand the role of cardiolipin in essential cellular functions, and how perturbation of cardiolipin synthesis leads to Barth syndrome. The second project focuses on identifying the molecular targets of lithium and valproate in order to elucidate the therapeutic mechanisms of action of the drugs in the treatment of bipolar disorder.

Presentation: Perturbation of the osmotic stress response in cardiolipin deficient mutants
(Scientific & Medical Session)

Thomas Haines, PhD — Visiting Professor of Biochemistry and Molecular Biology, Rockefeller University of New York, New York, NY, USA

Dr. Haines is a Visiting Professor of Biochemistry and Molecular Biology at the Rockefeller University of New York and Professor Emeritus of the City College of the City University of New York and the Graduate Center of CUNY.

His research has centered on understanding the unique roles of lipid structures in biological membranes. Medical applications of this work include why we make cholesterol/l polyunsaturated fatty acids and cardiolipin. He has recently focused on the role of the chains of cardiolipin in ATP synthesis.

Presentation: Cardiolipin's (CL's) pK2's suggest a role for CL in ATP synthesis *(Scientific & Medical Session)*

Xianlin Han, PhD — Assistant Professor of Medicine, Center for Cardiovascular Research, Washington University, St. Louis, MO, USA

Dr. Han is an Associate Professor in the Department of Internal Medicine, Washington University in St. Louis, a faculty member of the Division of Biology and Biomedical Sciences, and a member of the Executive Committee of the Alzheimer's Disease Research Center, Washington University School of Medicine. Dr. Han has broad research interests in understanding the role of membrane homeostasis in disease states. Currently, there are three specific areas explored in his laboratory: extension of the shotgun lipidomics technology for analysis of low abundance species of a cellular lipidome; identification of the biochemical mechanisms responsible for the sulfatide depletion at the very earliest stages of Alzheimer's disease; and identifying the biochemical mechanisms underlying the altered cardiolipin content and composition in diabetic myocardium. Dr. Han has a PhD from the Department of Chemistry of Washington University and has received several awards, including the Memory Ride Prize. He is a member of the American Society for Biochemistry and Molecular Biology and the Society for Neuroscience.

Presentation: Cardiolipin and shotgun lipidomics *(Scientific & Medical Session)*

Grant M. Hatch, PhD — Director of the Lipid Lipoprotein and Atherosclerosis Research Group; Professor, Department of Pharmacology and Therapeutics; Department of Biochemistry and Medical Genetics, University of Manitoba, Winnipeg, Canada; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc., Perry, FL, USA

Dr. Hatch is a Professor in the Departments of Pharmacology and Therapeutics and Biochemistry and Medical Genetics. He is also an Assistant Professor in the Department of Internal Medicine at the University of Manitoba. Dr. Hatch serves as the Director of the Lipid, Lipoprotein and Atherosclerosis Research Group and is a Managing Member of the University's Centre for Research and Treatment of Atherosclerosis. He is a Research Affiliate of the Centre on Aging and a member of the Manitoba Institute of Child Health. The focus of Dr. Hatch's research for the past 16 years has been to understand the regulation of cardiolipin and phospholipid metabolism in mammalian cells.

Dr. Hatch holds a BSc in Chemistry, and an MSc and a PhD in Biochemistry.

Chairman—Tafazzin and Cardiolipin (*Scientific & Medical Session)*

Kristin Hauff, BSc — Department of Pharmacology & Therapeutics, University of Manitoba, Winnipeg, Manitoba, Canada

After having completed a BSc in Microbiology at the University of Manitoba, Ms. Hauff is currently completing her PhD in the lab of Dr. Grant Hatch at the University of Manitoba, Department of Pharmacology. Her research is based on the mechanism of hypocholesterolemia seen in Barth syndrome, focusing on the biology of lymphoblasts.

Presentation: Hypocholesterolemia in Barth syndrome lymphoblasts *(Scientific & Medical Session)*

Marni L. Jacob — Clinical Psychology Graduate Student, Psychology Department, University of Georgia, Athens, GA, USA

Ms. Jacob is currently a doctoral student in clinical psychology at the University of Georgia. She has also worked in the obsessive-compulsive disorder treatment program at the University of Florida. Her research interests currently involve the study of emotion socialization in youth, treatment-outcome research for anxiety disorders, and the study of psychosocial factors associated with Barth syndrome.

Presentation: Psychosocial Aspects of Barth syndrome *(Family Session)*
Presentation: Bullying (*Affected Individual Session)*
Presentation: How Do I Explain Barth Syndrome *(Sibling Session)*

Robert E. Jensen, PhD — Professor, Cell Biology & Anatomy, Johns Hopkins School of Medicine, Baltimore, MD, USA

Dr. Jensen is Professor of Cell Biology at Johns Hopkins School of Medicine and the Center for Cell Dynamics at Johns Hopkins University. His research focuses on the basic cell and molecular biology of mitochondria, including protein import, mitochondrial division and fusion, and mitochondria DNA inheritance. His work also includes the search for the biochemical basis of human mitochondrial disorders, including a Barth-like disorder defective in the mitochondrial protein import machinery.

Presentation: A Barth-like disorder caused by a defect in mitochondrial protein import
(Scientific & Medical Session)

Richard I. Kelley, MD, PhD — 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; Chair, Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc., Perry, FL; Advisory Board, Barth Syndrome Registry & DNA Bank, Gainesville, FL, USA

Dr. Kelley is board certified in Pediatrics and Medical Genetics and specializes in the diagnosis and treatment of inborn errors of metabolism. His research focuses on the determination of the biochemical basis of both known and novel genetic disorders and on the treatment of selected diseases, including Barth syndrome, Smith-Lemli-Opitz syndrome, and disorders of mitochondrial metabolism. Dr. Kelley also is a co-founder of and consulting geneticist for the Clinic for Special Children, a charitable medical facility for the diagnosis and treatment of genetic disorders among the Amish and Mennonite populations of Lancaster, Pennsylvania.

Chairman—Model Systems and Clinical Factors *(Scientific & Medical Session)*
Chairman—Risks...Trends...Management *(Family Session)*

Rebecca L. Kern, MGC — Genetic Counselor, Department of Neurogenetics, Division of Metabolism, Kennedy Krieger Institute, Baltimore, MD, USA

Ms. Kern is a Genetic Counselor in the Division of Metabolism, Department of Neurogenetics at Kennedy Krieger Institute. She joined Dr. Kelley's team at Kennedy Krieger Institute in July of 2002 after graduating from the University of Maryland's Master's in Genetic Counseling Program. One of her primary roles is to assist with both clinical care and research involving families with Barth syndrome. She also triages inquiries for the Metabolism Clinic and coordinates the division's research projects. Other interests include new technologies and education relevant to newborn screening, preimplantation genetic diagnosis for single gene disorders, and neuropsychiatric genetics.

Presentation: Fun with Genetics *(Affected Individual & Sibling Sessions)*

Susan Kirwin — Senior Research Associate, Assistant Director, Nemours Children's Clinic, A. I. duPont Hospital, Wilmington, DE, USA

Ms. Kirwn's laboratory provides molecular diagnostic testing for a variety of muscular and neuromuscular diseases, primarily using pediatric patient samples from around the world for DNA, and more recently RNA, for sequencing various genes of interest. Her laboratory is interested in testing potential Barth syndrome patients through DNA and development of an RNA test that is supported through a recent BSF grant.

Presentation: What can we learn from mRNA analysis when *TAZ* mutation detection is negative?
(Scientific & Medical Session)

Willem Kulik, PhD — Senior Scientist (spectrometry/metabolomics), Academic Medical Centre, University of Amsterdam, Amsterdam, The Netherlands

Dr. Kulik specializes in hyphenated tandem mass spectrometry in metabolic research and diagnostics. Previous to his current position, Dr. Kulik worked from 1992 to 2002 at the Free University Hospital, Amsterdam, on stable isotopic techniques in nutrition, physiology and clinical studies based on hyphenated mass spectrometry. From 1990 to 1992, he carried out food chain research with mass spectrometry at RIKILT—Institute of Food Safety, Wapeningen, The Netherlands.

Presentation: Rapid biochemical detection of Barth syndrome using HPLC-tandem mass spectrometry
(Scientific & Medical Session)

Steven E. Lipshultz, MD — George Batchelor Professor and Chairman, Department of Pediatrics, Professor of Epidemiology and Public Health, Professor of Medicine (Oncology), Associate Executive Dean for Child Health, Leonard M. Miller School of Medicine, University of Miami; Chief-of-Staff, Holtz Children's Hospital of the University of Miami-Jackson Memorial Medical Center; Director, Batchelor Children's Research Institute; Associate Director, Mailman Institute for Child Development; and Member, the Sylvester Comprehensive Cancer Center, Miami, FL, USA

Dr. Lipshultz's primary research interests are in the pediatric cardiomyopathies, especially those of genetic/metabolic, toxic or infections/inflammatory etiologies. Clinical research on determinants of outcome for children with cardiovascular disease is also a major interest.

Dr. Lipshultz was previously a Professor of Pediatrics and Oncology, and Associate Chair of Pediatrics for Planning at the University of Rochester School of Medicine and Dentistry, Rochester, New York. While in Rochester, Dr. Lipshultz was the Chief of the Division of Pediatric Cardiology at the University of Rochester Medical Center and at the Golisano Children's Hospital at Strong, as well as Director of the Children's Heart Center at Strong from 1996 to 2003.

Presentation: Pediatric Cardiomyopathy Registry *(Scientific & Medical Session)*

Melissa Maisenbacher, MS, CGC — Pediatric Genetic Counselor, Department of Pediatrics, Division of Genetics, University of Florida, Gainesville, FL; Advisory Board, Barth Syndrome Registry and DNA Bank, Gainesville, FL, USA

Melissa Maisenbacher is an ACGME board-certified genetic counselor at the University of Florida. She works in the Congenital Heart Center and the Department of Pediatrics, Division of Genetics at UF. She is currently involved in research projects related to Barth syndrome, Pompe disease and newborn screening for congenital heart defects, in addition to her clinical work in Pediatric Genetics and the Cardiomyopathy clinics. She also serves on the board of the International 22q11.2 Foundation.

Ms Maisenbacher holds BS in Biology from University of Notre Dame and a MS in Genetic counseling from Arcadia University.

Presentation: Building a database – from the ground up! *(Family Session)*

Mindong Ren, PhD — Assistant Professor, Department of Cell Biology, New York University School of Medicine, New York, NY, USA

Dr. Ren's research interests include biogenesis of intracellular organelles and their derangement in disease. His research on Barth syndrome has been supported by the Barth Syndrome Foundation and the United Mitochondrial Diseases Foundation.

Dr. Ren holds MS and PhD degrees in Molecular Cell Biology from the Sackler Institute of Graduate Biomedical Sciences at New York University School of Medicine.

Presentation: Genetic suppressors of TAZ mutant phenotype in Drosophila—potential targets for therapy of Barth syndrome *(Scientific & Medical Session)*

Michael Schlame, MD — Associate Professor of Anesthesiology & Cell Biology, New York University School of Medicine, New York, NY; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc., Perry, FL; Medical Advisory Board, Barth Syndrome Registry & DNA Bank, Gainesville, FL, USA

Dr. Schlame is an Associate Professor of Anesthesiology & Cell Biology at New York University School of Medicine and Attending Anesthesiologist at New York University Medical Center. He is board certified in Anesthesiology both in the US and in Europe. Dr. Schlame trained at Charité University Hospital in Berlin, at New York Presbyterian Hospital, and at New York University Medical Center in New York. His subspecialties include cardiothoracic anesthesiology and critical care, and his research interests include Barth syndrome, lipids, and mitochondria. Dr. Schlame's clinical focus includes adult and pediatric critical care, cardiothoracic anesthesia, and pediatric anesthesia. His research interests include mitochondrial energy metabolism, pulmonary surfactant, cardiolipin, mechanisms of multiple organ failure, and cardiomyopathy.

Presentation: Function of tafazzin isoforms (*Scientific & Medical Session)*

Genevieve Sparagna, PhD — Department of Integrative Physiology, University of Colorado at Boulder; Pharmacology & Cardiology Departments, University of Colorado Denver and Health Science Center, Boulder, CO, USA

Dr. Sparagna received her undergraduate degree in Physics from MIT and her PhD in Biophysics from the University of Rochester under Dr. Thomas Gunter. Her specialty is mitochondrial function and she has been doing research on cardiolipin for the past 10 years, beginning in the laboratories of Dr. Jeanie McMillin and Dr. William Dowhan at the University of Texas Houston Health Science Center, where she did her postdoctoral training. She has two grants from the National Institute of Health, one from the American Heart Association (with Dr. Russell Moore) and one from the Barth Syndrome Foundation to study the alterations in remodeling of cardiolipin in heart failure and how it can be altered with changes in diet.

Presentation: Alterations in the cardiolipin profile leading to heart failure in a rat model and its restoration with diet *(Scientific & Medical Session)*

Carolyn T. Spencer, MD — Assistant Professor Pediatrics, Department of Cardiology, Children's Hospital, Boston, MA; Co-Principal Investigator, Barth Syndrome Registry and DNA Bank, Gainesville, FL, USA

Dr. Spencer's clinical practice and teaching have focused on echocardiography, exercise testing and cardiomyopathy. She is currently on the cardiology faculty in the echocardiography laboratory at Children's Hosptial Boston where she participates in performing, interpreting and teaching transthoracic and transesophageal echocardiography in all forms of congenital and acquired heart disease in the pediatric and adult congenital populations. She supervises in the exercise laboratory and participates in the clinical care of patients with cardiomyopathy and congenital heart disease at Children's Hospital Boston. Additionally, Dr. Spencer has initiated the Barth Syndrome Registry and DNA Bank to further translational research in this area and to encourage collaboration among scientists interested in Barth syndrome.

Chairman—Cardiac Aspects of Barth Syndrome *(Family Session)*
Presentation: Cardiomyopathy, skeletal myopathy and functional capacity in Barth syndrome *(Scientific & Medical Session)*

Jay St. Amant, MS — Department of Clinical and Health Psychology, University of Florida, Gainesville, FL, USA

Mr. St. Amant is a graduate student pursuing his PhD in Clinical Psychology from the Department of Clinical and Health Psychology at the University of Florida. He received his bachelor's degree from Mount Olive College in North Carolina and received his master's degree from the University of Florida. He has spent the past two years conducting research on quality of life in pediatric implantable cardioverter defibrillator (ICD) patients. It is his passion for children with ICDs that led him to become involved in research with Barth syndrome children and families under the guidance of Dr. Eric Storch.

Presentation: Day-to-Day Issues *(Family Session)*
Presentation: Bullying *(Affected Individual Session)*
Presentation: How Do I Explain Barth Syndrome *(Affected Individual & Sibling Sessions)*

Colin G. Steward, FRCP, FRCPCH, PhD — Bristol Royal Hospital for Children, Bristol, UK; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc., Perry, FL; Advisory Board, Barth Syndrome Registry & DNA Bank, Gainesville, FL, USA

Dr. Steward is Reader in Stem Cell Transplantation at the University of Bristol, England and a member of the Scientific & Medical Advisory Board and the Database and Biobank Steering Committee of BSF. He specializes in genetic diseases affecting the blood and bone marrow, and first became interested in Barth syndrome after realizing that his department had missed the correct diagnosis in several boys with neutropenia. He has since diagnosed nine further families presenting with the disease in South West England and Wales, and organizes annual specialist clinics for affected families from across the UK. Dr. Steward believes that Barth syndrome is seriously under-diagnosed because it presents in many different ways, and is working to raise awareness of the disease. For example, at this conference he will be talking about Barth syndrome as a cause of fetal death, stillbirth and miscarriage.

Chairman—Hematological Aspects of Barth syndrome *(Family Session)*
Presentation: Foetal hydrops, cardiomyopathy and death due to Barth syndrome *(Scientific & Medical Session)*

Matthew J. Toth, PhD — Science Director, Barth Syndrome Foundation, Inc.; *Ex-officio*, Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc., Perry, FL; Advisory Board, Barth Syndrome Registry & DNA Bank, Gainesville, FL, USA

Dr. Toth received his PhD in Microbiology from Massachusetts Institute of Technology (MIT) and joined a large pharmaceutical company where he was part of several teams involved with drug discovery projects in the areas of inflammation and cardiovascular diseases. He focused his laboratory's expertise on making and testing genetically altered mice as a way to advance these drug discovery programs. After joining a smaller pharmaceutical company and eventually a biotech company, Dr. Toth led several drug discovery programs in the areas of pain and orphan diseases. In July of 2006 he joined the BSF Inc. as Science Director to use his experience in guiding efforts towards finding a treatment for Barth syndrome.

Chairman: Report on Research *(Family Session)*

Beverly Tsai-Goodman, BM, MRCP, MD — Consultant Paediatric Cardiologist and Foetal Cardiologist, Bristol Royal Hospital for Children, Bristol, UK

Dr. Tsai-Goodman's main research interest lies with imaging, both 2D/3D echocardiography and cardiac MRI, and fetal cardiology. She is very much involved with the boys with Barth syndrome in the UK from the cardiac standpoint. She reviews these children in the Barth Clinic held annually in Bristol. She is also involved in compiling a consensus statement on the management of cardiac disease in children with 22q11 deletion syndrome.

Dr Tsai-Goodman's research project for her doctoral degree at the University of Bristol was entitled 'Non-invasive cardiac output measurement in newborn infants'.

Chairman—Report on Research *(Family Session)*
Presentation: Cardiology of Barth syndrome *(Scientific & Medical Session)*

Frédéric M. Vaz, PhD — Departments of Pediatrics & Clinical Chemistry, University of Amsterdam, Amsterdam, The Netherlands

Dr. Vaz finished his Chemistry MSc at the University of Utrecht in 1997. Under the supervision of Prof. Ronald Wanders in the Laboratory Genetic Metabolic Diseases he obtained his PhD degree in 2002 at the University of Amsterdam. The main focus of his research has been Barth syndrome, funded by grants of the Barth Syndrome Foundation and the Princess Beatrix Foundation. He investigated the cardiolipin abnormalities in Barth syndrome using tandem mass spectrometry and studied the function of tafazzin, the defective protein in this disorder. In 2004 he became a Clinical Chemist in training at the Department of Clinical Chemistry at the Academic Medical Center but continued his research on Barth syndrome in collaboration with Willem Kulik on projects funded by grants of the Barth Syndrome Foundation and Princess Beatrix Foundation.

Presentation: Proteomic analysis of the consequences of tafazzin-deficiency in *S. cerevisiae*
(Scientific & Medical Session)

Ronald J.A. Wanders, PhD — Professor of Enzymology & Inherited Metabolic Disorders, University of Amsterdam, The Netherlands; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc., Perry, FL, USA

Dr. Wanders studied Chemistry at the University of Amsterdam, with Biochemistry as subspecialization. Subsequently, he accepted a PhD position at the E.C. Slater Institute for Biochemical Research, Department of Biochemistry, University of Amsterdam and performed research on different aspects of mitochondrial metabolism, especially oxidative phosphorylation, under the leadership of Prof. Joseph M. Tager, as PhD supervisor. Subsequently, Dr. Wanders accepted a Postdoc position at the Laboratory for Genetic Metabolic Diseases, Departments of Clinical Chemistry and Pediatrics, Faculty of Medicine, University of Amsterdam, with a joint task to (1) set up an enzymatic diagnostic laboratory for the enzymatic diagnosis of different inborn errors of metabolism, notably peroxisomal disorders and mitochondrial fatty acid oxidation defects, and (2) perform fundamental research.

Prof. Wanders heads the renowned Laboratory for Genetic Metabolic Diseases at AMC in Amsterdam. Several scientists in this lab have conducted interesting projects concerning the underlying biochemical causes of Barth syndrome and have done other work that is relevant to a fuller understanding of this disorder.

Chairman: Population and Functional Screening *(Scientific & Medical Session)*

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Barth Syndrome: *On Track Toward a Cure*

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