



Barth Syndrome
Foundation

Cracking the Mysteries of Barth Syndrome

**Third International Scientific,
Medical and Family Conference**

Sponsored by

The Barth Syndrome Foundation, Inc., and Affiliates

www.barthsyndrome.org



July 3-8, 2006

***Disney's Coronado Springs Resort
Lake Buena Vista, Florida***



Welcome

Dear Participants,

On behalf of the Barth Syndrome Foundation, I would like to welcome you to our 3rd Biennial International Conference. This event promises to be an interactive, thought provoking meeting. It will stimulate strategic thinking of future approaches in research, diagnosis and treatment therapies. To accomplish our ultimate goal to save lives, it will require a team of partners. No advances in any of these matters can be made without the vital collaborations between basic science, medicine, and families.

Our first step in this effort must be to draw upon the collective wisdom within our community to consider the mysteries that still abound about Barth syndrome. While much has been learned in the ten years since the discovery of the *TAZ* gene, we must challenge ourselves with all our might. Though it may be through varied scope, mysteries are present in all our stories. We intend to use this conference to accelerate an exchange of information and ideas among families, scientists and clinicians who are dedicated to those who have Barth syndrome.

We have invited all principal physicians and scientists from around the world who are working on the major biochemical and clinical aspects of the disorder to ponder these great mysteries. We have also called upon these experts to address the pressing concerns of the families. Unlike any other health organization, we have taken great strides to create an agenda for the youth within our community. The young men who have Barth syndrome are the ones who will most benefit from these advances. Their brothers and sisters may not have Barth syndrome but they have witnessed it firsthand, grown up with it, and have concerns unique amongst their peers.

It is fitting that our keynote speaker will be Dr. Roberto Canessa, a pediatric cardiologist from Montevideo, Uruguay. His inspirational presentation will challenge all conferees to appreciate the essential element of teamwork. Dr. Canessa is best known for being a part of one of the most amazing survival stories in the 20th century. In 1972, a plane carrying Roberto, then aged 19, along with his rugby teammates, crashed in the Andes Mountains. The survivors endured below freezing temperatures and isolation for 72 days. Over the 34 years since that event, Dr. Canessa and his wife Laura have dedicated themselves by inspiring others to seek solutions, even when confronted with great adversity.

Barth syndrome is described as a complex, multi-system disorder. One cannot underestimate the equally multi-faceted challenges encountered in terms of determination, will and hope. We cannot consider the science without considering the spirit. Thank you for being a part of our team. Together is the only way we can ever unravel the mysteries of Barth syndrome and arrive upon much needed solutions.

Foreword



Welcome to the Third International Scientific/Medical & Family Conference. We are sure that you will enjoy the conference and will gain much that is useful. The following pages outline the programs for the conference and provide short introductions to the speakers. The conference follows two separate tracks. One track is designed for scientific and medical professionals and the other track focuses on the needs of families affected by Barth syndrome. There is also a track for siblings.

For the Scientific/Medical track, see pages headed Scientific and Medical Sessions, which occur on Wednesday (Registration), Thursday, Friday and Saturday, July 5 to 8, 2006. For the Family track, see pages headed Family Sessions, which occur on Monday to Wednesday (Registration and Clinics), July 3 to 5, 2006 and Thursday to Saturday, July 6 to 8, 2006. For those youth who have Barth syndrome and those youth who have brothers with Barth syndrome, see pages headed "Those with Barth Syndrome" and "Those Who Have Brothers With Barth Syndrome", which occur on Monday to Wednesday (Registration and Clinics), July 3 to 5, 2006 and Thursday to Saturday, July 6 to 8, 2006.



December 1972

KEYNOTE SPEAKER: ROBERTO CANESSA, M.D.

"Around me, everything was a nightmare."

An outstanding rugby player who played for his country, and also for South America in 1978, Dr. Roberto Canessa still holds the record of Top Try Scorer in Uruguay.

In 1972, the plane carrying Dr. Canessa and a delegation of his rugby club, Old Christians, crashed in the Andes on their way to Chile. At 3,500 meters above sea level and with temperatures below freezing, without any source of food and no contact with civilization, after 72 days, only 16 of the 45 passengers survived to tell the story.

The dynamics of human groups in situations of crisis has led to many theories about leadership, team search of solutions, optimization of the qualities of each individual in a team. However, the Andes experience is a unique real life story, where a group of ordinary people encountered an extreme situation, and found admirable solutions. You will have the opportunity to hear Roberto personally tell this story and share the lessons of this incredible ordeal.



July 2006

Barth Syndrome Foundation, Inc.
Scientific and Medical Advisory Board

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chairman
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Baltimore, MD

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Emma Children's Hospital / AMC
Amsterdam, The Netherlands

Barry J. Byrne, MD, PhD
Pediatric Cardiology
Shands Children's Hospital
University of Florida
Gainesville, FL

Gerald F. Cox, MD, PhD
Clinical Genetics
Children's Hospital
Boston, MA
Clinical Research, Genzyme Corp.
Cambridge, MA

Salvatore DiMauro, MD
Neurology
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Molecular Diagnostics Lab (*retired*)
A. I. DuPont Hospital for Children
Wilmington, DE

Miriam L. Greenberg, PhD
Biological Sciences
Wayne State University
Detroit, MI

Grant M. Hatch, PhD
Lipid Lipoprotein Research
University of Manitoba
Winnipeg, Canada

Michael Schlame, MD
Anesthesiology
NYU School of Medicine
New York, NY

**Colin G. Steward, MA, BM, BCh,
FRCP, FRCPC, PhD**
Pediatric Hematology
Bristol Royal Hosp. for Children
Bristol, England

Jeffrey A. Towbin, MD
Pediatric Cardiology
Texas Children's Hospital
Baylor College of Medicine
Houston, TX

Ronald J. A. Wanders, PhD
Genetic Metabolic Diseases
Academic Medical Center
Amsterdam, The Netherlands

Katherine R. McCurdy – *ex officio*
Science and Medicine
Barth Syndrome Foundation, Inc.
New York

Barth Syndrome Foundation, Inc.

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We acknowledge, with many thanks, our sponsors:

The National Heart, Lung, and Blood Institute,
National Institutes of Health

The Office of Rare Diseases,
National Institutes of Health

Holman Enterprise

Barth Syndrome Trust (UK & Europe)
Barth Syndrome Foundation of Canada
Barth Trust of South Africa

United Space Alliance
USA Employee One Fund

Tracks for Barth Syndrome Foundation 2006 International Conference

6/21/2006

Track: Science and Medicine

July 5th – 6th 2006

Specifically designed to expand beyond current knowledge to unravel the mysteries that exist about Barth syndrome

Section 1 Gene Products and Biochemistry

Section 2 New Frontiers in Barth Science

Section 3 Cardiac Issues

Section 4 Hematological Issues

Section 5 Development of Barth Syndrome Treatment Guidelines

Track: Families

July 5th – 6th 2006

Section: Adults

Specifically designed to address the lay adult audience

Emphasis: Clinical Aspects of Barth Syndrome
Research Advances
Opportunities to Propel Research
Family Dynamics
Day-to-Day Aspects of Barth Syndrome

Target Audience: Parents
Grandparents
Extended Family Members
Adult Affected Individuals
Adult Siblings

Section: Youth

Youth 1: Designed to address the needs of youth ages 8+
Emphasis: Varies between age groups
Target Audience: Youth who have Barth syndrome

Youth 2: Designed to address the needs of youth ages 8+
Emphasis: Varies between age groups
Target Audience: Youth who have a brother with Barth syndrome

Conference Committee

Chair.....Jan Kugelmann
Registration.....Lois Galbraith
Clinics.....Valerie M. Bowen

Science & Medicine

.....Katherine R. McCurdy
.....Dr. Richard I. Kelley
.....Dr. Miriam L. Greenberg
.....Dr. Michael Schlame
.....Dr. Colin G. Steward
.....Dr. Jeffrey A. Towbin

Family Advocacy.....Shelia Mann

Youth Sessions

.....Christiane Hope
.....Alanna Layton
.....Mary Pat Draddy
.....Eileen Juico

Social Event.....Lynda Sedefian and Joyce Lochner

Public Relations.....Susan Osnos and Alanna Layton

Multi-Media Resources

.....Lynn Elwood
.....Jeannette Thorpe
.....Michaela Damin

Global Awareness

Barth Syndrome Trust (UK & Europe)
Barth Syndrome Foundation of Canada
Barth Trust of South Africa

Travel Awards

Jeannette Thorpe (Chair, Barth Trust of South Africa)
Michaela Damin (Chair, Barth Syndrome Trust)

Scientific & Medical Sessions

Wednesday, July 5, 2006

16:00 – 20:00 ~ Registration (South Registration Counter)

Thursday, July 6, 2006

7:00 – 8:00 Registration (South Registration Counter)

Location: Fiesta 1-3

7:00 – 8:00 MORNING COFFEE & DANISH

8:00 – 8:10 **Welcome and Opening Remarks**
~ Katherine R. McCurdy - V.P. Science and Medicine,
Barth Syndrome Foundation, Inc.

8:10 – 8:15 **Perspective on this Meeting**
*Chair: Richard I. Kelley, M.D., Ph.D. - Kennedy Krieger
Institute, affiliate of Johns Hopkins Medical
Institutions, Baltimore, MD*

8:15 – 12:40 **GENE PRODUCTS AND BIOCHEMISTRY OF BARTH
SYNDROME**
*Chairs: Miriam L. Greenberg, Ph.D. and Michael
Schlame, M.D.*

8:15 – 8:20 **Barth Family Personal Introduction**
~ Scott Oldewage - Barth Syndrome Foundation, Inc.

8:20 – 8:30 **Introduction to this Portion of the Conference and Its
Speakers**
~ Miriam L. Greenberg, Ph.D. – Wayne State University,
Detroit, MI

8:30 – 9:00 **Drosophila Model of Barth Syndrome: Genetics and
Cell Biology**
~ Mindong Ren, Ph.D. – New York University, New York,
NY

9:00 – 9:30 **Drosophila Model of Barth Syndrome: Tafazzin
Enzymology, Mitochondrial Morphology, and Flight
Muscle Physiology**
~ Michael Schlame, M.D. – New York University Hospital,
New York, NY

9:30 – 10:00 **Animal Models of Barth Syndrome**
~ Arnold W. Strauss, M.D. – Vanderbilt University,
Nashville, TN

10:00 – 10:30 **Protein Complexes of the Inner Mitochondrial
Membrane are Affected by Loss of Taz1 Function**
~ Peter Rehling, Ph.D. – Albert-Ludwigs University of
Freiburg, Freiburg, Germany

10:30 – 10:45 BREAK

10:45 – 11:15 **Characterization of the Saccharomyces Cerevisiae
Tafazzin**
~ Eric Testet, Ph.D. – University of Bordeaux 2, Membrane
Biogenesis Laboratory, Bordeaux, France

11:15 – 11:45 **In Vitro Characterization of Tafazzin Enzymatic
Function**
~ Tal M. Lewin, Ph.D. – University of North Carolina,
Chapel Hill, NC

11:45 – 12:15 **The Cellular Consequences of Cardiolipin Deficiency**
~ Miriam L. Greenberg, Ph.D. – Wayne State University,
Detroit, MI

12:15 – 12:40 **How Can We Best Move Ahead to Solve These
Mysteries?**
~ Miriam L. Greenberg, Ph.D. – Wayne State University,
Detroit, MI
~ Michael Schlame, M.D. – New York University Hospital,
New York, NY

Location: Coronado A-C

12:45 – 13:30 LUNCH

Scientific & Medical Sessions

Thursday, July 6, 2006 (cont'd)

Location: Fiesta 1-3

- 13:35 – 16:25 **NEW FRONTIERS OF BARTH SYNDROME SCIENCE**
Chair: Richard I. Kelley, M.D., Ph.D. – Kennedy Krieger Institute, affiliate of Johns Hopkins Medical Institutions, Baltimore, MD
- 13:35 – 13:40 **Barth Family Personal Introduction**
~ Catharine L. Ritter - Barth Syndrome Foundation of Canada
- 13:40 – 13:45 **Introduction to this Portion of the Conference and Its Speakers**
~ Richard I. Kelley, M.D., Ph.D. – Kennedy Krieger Institute, affiliate of Johns Hopkins Medical Institutions, Baltimore, MD
- 13:45 – 14:15 **Clinical and Metabolic Features of an Autosomal Recessive Phenocopy of Barth Syndrome**
~ Francois P. Bernier, M.D. – University of Calgary, Calgary, Alberta, Canada
- 14:15 – 14:45 **The Role of the Human Timm14 Protein in Barth Syndrome**
~ Robert E. Jensen, Ph.D. – Johns Hopkins University, Baltimore, MD
- 14:45 – 15:15 **“Of Phospholipid Fables and Fatty Acid Tales: Implications for Barth Syndrome**
~ Grant M. Hatch, Ph.D. – University of Manitoba, Winnipeg, Manitoba, Canada
- 15:15 – 15:45 **Barth Syndrome: Linking the Biochemistry to the Disease**
~ Richard I. Kelley, M.D., Ph.D. – Kennedy Krieger Institute, affiliate of Johns Hopkins Medical Institutions, Baltimore, MD
- 15:45 – 16:10 **“Where Do We Go From Here?”**
~ Richard I. Kelley, M.D., Ph.D. – Kennedy Krieger Institute, affiliate of Johns Hopkins Medical Institutions, Baltimore, MD



16:15 – 16:30 **BREAK (Outside of Fiesta 5)**

Location: Fiesta 5

16:30 – 18:00 **KEYNOTE ADDRESS**
“Team Building and Group Dynamics in Crisis Situations”
~ Roberto Canessa, M.D. – Pediatric Cardiologist, Montevideo, Uruguay
**** Combined Session with BSF Families (and children 12+)**

Location: Fiesta 5

18:00 – 20:00 **POSTER SESSION** (with authors standing by their posters and available for discussion)
~ Wine and Cheese served

Scientific & Medical Sessions

Friday, July 7, 2006

Location: Fiesta 1-3

- 7:30 – 8:00 **MORNING COFFEE AND DANISH**
- 8:00 – 12:00 **CARDIAC ISSUES OF BARTH SYNDROME**
Chair: Jeffrey A. Towbin, M.D., Texas Children's Hospital, Houston, TX
- 8:00 – 8:05 **Barth Family Personal Introduction**
~ Michaela Damin, Barth Syndrome Trust
- 8:05 – 8:15 **Introduction to this Portion of the Conference and Its Speakers**
~ Jeffrey A. Towbin, M.D., Texas Children's Hospital, Houston, TX
- 8:15 – 8:45 **Different Forms of Heart Disease in Barth Syndrome**
~ Jeffrey A. Towbin, M.D., Texas Children's Hospital, Houston, TX
- 8:45 – 9:15 **Barth Syndrome Cardiomyopathy – Data from BSF Funded Project**
~ Carolyn T. Spencer, M.D. – Shands Children's Hospital, Gainesville, FL
- 9:15 – 9:45 **Mechanisms of Cardiac Disease in Barth Syndrome**
~ Arnold W. Strauss, M.D. – Vanderbilt Children's Hospital, Nashville, TN
- 9:45 – 10:15 **Cardiac Arrhythmias and Barth Syndrome**
~ Randall M. Bryant, M.D. – Shands Children's Hospital, Gainesville, FL
- 10:15 – 10:30 **BREAK**

Location: Fiesta 1-3

- 10:30 – 11:00 **Cardiomyopathy and Heart Failure**
~ Robert E. Shaddy, M.D. – Primary Children's Medical Center, Salt Lake City, UT
- 11:00 – 11:30 **Novel Cardiac Diagnostic Approaches**
~ Tal Geva, M.D. – Children's Hospital, Boston, MA
- 11:30 – 12:00 **What Needs to be Done Next?**
~ Jeffrey A. Towbin, M.D., Texas Children's Hospital, Houston, TX

Location: Fiesta 5

- 12:00 – 13:00 **LUNCH with Barth Syndrome Families**
- 13:05 – 15:40 **HEMATOLOGICAL ASPECTS OF BARTH SYNDROME**
Chair: Colin G. Steward, M.A., B.M., B.Ch., F.R.C.P., F.R.C.P.C.H., Ph.D., Bristol Royal Hospital, Bristol, UK
- 13:05 – 13:10 **Barth Family Personal Introduction"**
~ William R. McCurdy - Barth Syndrome Foundation, Inc.
- 13:10 – 13:15 **Introduction to this Portion of the Conference and Its Speakers**
~ Colin G. Steward, M.A., B.M., B.Ch., F.R.C.P., F.R.C.P.C.H., Ph.D., Bristol Royal Hospital, Bristol, UK
- 13:15 – 13:45 **Review of Patient Studies of Neutropenia in Barth Syndrome**
~ Colin G. Steward, M.A., B.M., B.Ch., F.R.C.P., F.R.C.P.C.H., Ph.D., Bristol Royal Hospital, Bristol, UK
- 13:45 – 14:15 **Frontiers of Neutrophil Research**
~ David C. Dale, M.D. – University of Washington, Seattle, WA

Scientific & Medical Sessions

Friday, July 7, 2006 (cont'd)

Location: Fiesta 1-3

14:15 – 14:45 Energy Supply in Neutrophils

~ Taco W. Kuijpers, M.D. – Emma Children's Hospital, Amsterdam, The Netherlands

14:45 – 15:15 Reduction of Cardiolipin (CL) Per Se Does Not Mimic the Effects on Cell Death Associated with CL Remodeling in Barth Syndrome Lymphoblasts

~ Patrice X. Petit, Ph.D. – Institute Cochin, Paris, France

15:15 – 15:40 What is on the Horizon?

~ Colin G. Steward, M.A., B.M., B.Ch., F.R.C.P., F.R.C.P.C.H., Ph.D.
~ David C. Dale, M.D. – University of Washington, Seattle, WA

15:40 – 16:00 BREAK

16:00 – 16:30 BARTH SYNDROME MEDICAL DATABASE AND BIOREPOSITORY

“Creation of the Barth Syndrome Medical Database and Biorepository”

~ Carolyn T. Spencer, M.D. – Principal Investigator, Barth Syndrome Medical Database and Biorepository, University of Florida, Gainesville, FL

~ Valerie M. Bowen – President, Barth Syndrome Foundation, Inc.

16:30 – 17:00 MEETING SUMMARY AND THOUGHTS FOR THE FUTURE

“Surmounting the Obstacles and Charting the Way Forward”

~ Richard I. Kelley, M.D., Ph.D., Kennedy Krieger Institute, affiliate of Johns Hopkins Medical Institutions, Baltimore, MD

~ Miriam L. Greenberg, Ph.D., Wayne State University, Detroit, MI

~ Michael Schlame, M.D., New York University Hospital, New York, NY

~ Jeffrey A. Towbin, M.D., Texas Children's Hospital, Houston, TX

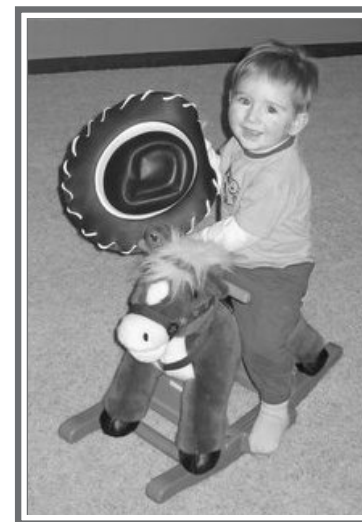
~ Colin G. Steward, M.A., B.M., B.Ch., F.R.C.P., F.R.C.P.C.H., Ph.D., Bristol Royal Hospital, Bristol, UK

17:00 – 18:30 - FREE TIME

Location: Fiesta 5

18:30 – 23:00

BUFFET DINNER AND SOCIAL EVENT FOR ALL



**Barth Syndrome
Foundation of Canada**

Scientific & Medical Sessions

Saturday, July 8, 2006

Location: Coronado E

8:00 – 10:00 MEETING OF BSF'S SCIENTIFIC AND MEDICAL ADVISORY BOARD
(Light breakfast served)

8:00 – 10:00 FREE TIME for Those NOT on BSF's Scientific and Medical Advisory Board

Location: Coronado F-G

10:00 – 15:30 WORKING SESSIONS (Lunch served)

UPDATE OF BARTH SYNDROME DIAGNOSIS CRITERIA AND DEVELOPMENT OF TREATMENT GUIDELINES

What is Barth syndrome? (What are the criteria for diagnosis?)

Further development of treatment guidelines (in groups)

- Cardiology (including electrophysiology)
- Hematology
- Neurology
- Metabolics
- Anesthesiology (virtually completed)

Reconvene and discuss the components and the whole child

Discuss publication/distribution

WORKING SESSION

Barth Syndrome Medical Database, Biorepository and Coordination of Barth Clinics

- Discuss data collection (methodology, obstacles, possible involvement of various Barth clinics, possible travel, etc.)
- Data use
- Biological samples (collection and use)
- Gene mutation database

Location: Coronado J

16:00 – 17:00 CLOSING SESSION – *Combined Session with Barth Syndrome Families*



Upcoming Medical Conferences Where BSF Will Be Present:

October 18 – 21, 2006
35th Annual Child Neurology Society Meeting
Pittsburgh, PA

December 9 – 12, 2006
The American Society of Hematology 48th
Annual Meeting & Expo
Orlando, FL

Important Facts

Barth Syndrome Multi-Disciplinary Clinics



We are delighted to announce that BSF will once again be offering multi-disciplinary clinics for affected individuals. This year our clinics are being expanded to include more sub-specialists for clinical assessments. You will have the opportunity to consult with many of the world's experts in all components of the disorder in one location and at no cost to your family!

Clinics being offered include: Cardiology; Neurology; Genetics; Education; Psychosocial; OT/PT; Financial consultant; Nutrition, including risk potential for hypoglycemia and osteoporosis; and

Planning ahead for the unexpected emergency.

BSF is not offering childcare on the days of the clinics; however, in an effort to make the most of these two days, we have worked with a professional child life specialist to design age-appropriate arts & crafts and game activities in Fiesta 5 & 6 where clinics are held. Some of the highlights include past favorites of face painting, balloon art, board games, banner decoration and much more. Siblings are encouraged to come and have fun!

What to Expect From BSF Clinics

Overview:

Clinicians who are involved in the BSF clinics will be collecting massive quantities of data on your child over a period of two days. The collection of data is just the beginning of the process. The next stage is to analyze the data case-by-case then add the quantified data into a database which can then be aggregated with other BTHS patients. These data are then compared with controls to determine the clinical phenotype of Barth syndrome. The information must be abstracted, hand entered and evaluated.

Benefits:

This conference will mark the 4th year longitudinal data have been collected on the largest cohort of individuals with Barth syndrome in the world. These studies have illuminated trends which had previously not been described. Life-threatening risks have been reported to the medical community. Relationships have been built between the Principal Investigator and hometown physicians. Centers are now collaborating to compare findings and develop a strategy for future research.

Photography

When we learned Kelly LaDuke could not join us for our 2006 conference we were disheartened. The images she captured at our 2004 Conference have provided us with an unpredictable invaluable resource. The portraits are more inspiring than any words; they speak volumes. The best that human nature can offer is evident in each of these boys and men, even through difficult circumstances. These boys and young men are inspirational. It is apparent we are not here because of a disorder; we are here because of the people affected by it. This is abundantly clear by a glimpse of their soul, captured in a split second through the lens of a camera. Amanda Clark was immediately inspired by Kelly's images. As an artist in her own rite, Amanda immediately realized the need to continue on with this project.



Amanda Clark has always had a passion for photography. A gift from a true love instilled in her a genuine love of others; to repay this blessing she gives people a true love gift that will last a lifetime. In 1981 she

received a camera as a gift from her husband, Joey. She had so much fun with it, never knowing that one day this would become her true love. Little did she know what was ahead of her, as Joey was murdered three weeks after they were married. Amanda continued to pick up the pieces and fell in love again in time. Her wonderful husband of 20 years, Bishop Clark, has always been supportive of her talent and when their two children were older, he encouraged her to start her own photography business. "...Each of us has a talent, and I thank you for allowing me to share with you my love for people and a gift God has given me."

Important Facts

Childcare *(Location: Fiesta 6)*

Pre-Registration for childcare will be held during the clinics (Fiesta 5 & 6) on Wednesday, July 5th, from 8:00 - 12:00 pm.

All children under the age of eight (8) should be registered. It is required that a parent or guardian register their child, as well as check-in and check-out. No other person will be permitted to do so unless specified on the registration form.

If your child does not want to participate in Thursday's Keynote Speaker Address (recommended for children over age 12), childcare will be available. You must pre-register your child for this event.

Children under the age of 3 must be accompanied by an adult/guardian during Monday's Movie Night and Wednesday evening's Kid's Dance Party.

Pre-Registration: Wednesday, July 5 (8:00-12:00 only!)
***During clinics in Fiesta 5 & 6*

Registration:
Thursday, Friday and Saturday, July 6, 7, 8 @ 9:00 am

Check-in will take place each morning in the Fiesta's Ballroom Foyer (outside of Fiesta 6)



Stay in the Loop

Don't worry about having to go anywhere by yourself after hours. Stop by the registration booth and let us know where you are going and details about a meeting spot and we can let others know "Who will be where?" after hours. This is not mandatory but it is a great way to get to know other conferees. We will maintain a running "What's Happening List" each day and share this information with you.



**Barth Syndrome
Trust**

Family Sessions

BSF Family Gathering

Join us on Wednesday Night...

Please join us for an informal gathering and discussion for Barth families to meet each other, talk and brainstorm about how BSF is doing! What is the Foundation doing well? What things are helpful to you and your family? How can we improve? We would LOVE to have your help and input — this will be a great opportunity before the meetings start for us to get together and think together about how BSF can continue to grow and prosper for the good of all of our families. Hope to see you there — we need you!

Wednesday, July 5th: 7:00 pm — 9:00 pm

Location: Coronado R & T

*****During this meeting entertainment will be provided for our youths/young adults. Please see below...***



Wednesday, July 5th: 7:00 pm — 9:00 pm

Location: Durango 1 & 2

Entertainment for the youth (all ages) will be provided by Renee Adams, who currently works as an interactive DJ/independent contractor for Walt Disney World, Sea World, Disney Cruise Lines, etc. Especially good with kids and families,

a few years ago she wrote and published her own children's book, which is currently being pitched for a new television series.

Monday July 3rd

Location: Monterey 1-3

18:30 – 21:00 Family Registration/Welcome Reception

Location: Yucatan 2 & 3

18:30 – 21:00 KIDS' MOVIE NIGHT (All Ages)

(*Children age 3 and under must be accompanied by an adult)

Tuesday, July 4th

Location: Fiesta 5 & 6

7:00 – 17:00 CLINICS/CONSULTS

LUNCH & DINNER ON YOUR OWN

Wednesday, July 5th

Location: Fiesta 5 & 6

7:00 – 17:00 CLINICS/CONSULTS

LUNCH & DINNER ON YOUR OWN

Location: Coronado R-T

19:00 – 21:30 BSF FAMILY MEETING

Location: Durango 1 & 2

19:00 – 21:30 CHAPERONED YOUTH GATHERING

~ Entertainment provided by Renee Adams

Family Sessions

Thursday, July 6, 2006

Location: South Registration Counter

7:00 – 16:30 REGISTRATION DESK OPEN

8:15 – 9:30 BREAKFAST BUFFET (Fiesta 5)

Location: Fiesta 7,8,9,10

9:45 – 10:00 OPENING REMARKS

~ Valerie M. Bowen, President, BSF

10:00 – 12:00 CARDIAC ASPECTS OF BARTH SYNDROME

Chair: Barry J. Byrne, M.D., Ph.D., University of Florida, Gainesville FL

10:00 – 10:15 Introduction into Echocardiograms and Electrocardiograms

~ Sharon Redfearn, A.R.N.P., University of Florida, Jacksonville, FL
~ Sharon Chapman, R.V.S., University of Florida, Gainesville, FL

10:15 – 10:20 Introduction: Clinical Challenges of Crisis Cardiac Management; Blending Knowledge about Barth Syndrome and Cardiomyopathy

~ Barry J. Byrne, M.D., Ph.D., University of Florida, Gainesville, FL

10:20 – 10:30 What we Know and What we Need to Determine about the Cardiomyopathy of Barth Syndrome

~ Carolyn T. Spencer, M.D., University of Florida, Gainesville, FL

10:30 – 10:40 What we Know and What We Need to Determine about Electrophysiology of Barth Syndrome

~ Randall M. Bryant, M.D., University of Florida, Jacksonville, FL

10:40 – 10:50 Approaches to Heart Failure; Past, Present and Future, Transplants in Barth Patients

~ Robert E. Shaddy, M.D., University of Utah, Salt Lake City, UT

10:50 – 12:00 Cardiology Panel Discussion (followed by Q&A's)
Moderator: Barry Byrne, M.D., Ph.D., University of Florida, Gainesville, FL

12:00 – 13:15 LUNCH (Fiesta 5)

Location: Fiesta 7,8,9,10

13:30 – 15:00 BARTH SYNDROME MEDICAL DATABASE AND BIOREPOSITORY

Chair: Valerie M. Bowen, President, Barth Syndrome Foundation, Inc. (BSF)

13:30 – 13:40 Introduction; Key Roles

~ Valerie M. Bowen, President, BSF

13:40 – 13:50 The Process of Defining the Appropriate Model for the Barth Syndrome Medical Database and Biorepository:

~ Lynn Elwood, President, Barth Syndrome Foundation of Canada; Project Manager in Development

13:50 – 14:05 The Process and the Prospects

~ Carolyn T. Spencer, M.D., University of Florida, Gainesville; Principal Investigator and Chair, Barth Syndrome Medical Database and Biorepository

14:05 – 14:20 Abstracting Data from Years of Records

~ Melissa K. Maisenbacher, M.S., C.G.C., University of Florida; Genetic Counselor, Data Abstractor and Research, Gainesville, FL

Family Sessions

Thursday, July 6, 2006 (cont'd)

Location: Fiesta 7,8,9,10

- 14:20 – 14:35 **Surveys Versus Formal Medical Database**
~ Elizabeth Shenkman, Ph.D., Institute of Child Health Policy, University of Florida (Biostatistics)
- 14:35 – 14:45 **Barth Syndrome Medical Database and Biorepository Panel Discussion; (followed by Q&A's)**
Moderator: Valerie M. Bowen, President, BSF
- 14:45 – 16:00 **BARTH SYNDROME; A JEANS TO GENES OVERVIEW**
Chair: Iris L. Gonzalez, Ph.D., Molecular Diagnostics Laboratory, A. I. DuPont Hospital for Children, Wilmington, DE (retired)
- 14:45 – 14:55 **Introduction; Research versus Diagnostic Facility, What Every Parent Should Know**
~ Iris L. Gonzalez, Ph.D., A. I. DuPont Hospital for Children, Wilmington, DE (retired)
- 14:55 – 15:05 **The Clinician's Role in Making a Diagnosis; Building a Case Through the Collection of Clinical and Biochemical Data**
~ Rebecca I. Kern, M.G.C., Kennedy Krieger Institute
- 15:05 – 15:15 **The Molecular Geneticist's Role in Obtaining a Diagnosis**
~ Karla R. Bowles, Ph.D., F.A.C.M.G., John Walsh Cardiovascular Diagnostic Laboratory, Baylor College of Medicine, Houston, TX
- 15:15 – 15:25 **The Parent's Perspective**
~ Keli Holly, Parent of two children with Barth syndrome



Location: Fiesta 7,8,9,10

- 15:25 – 15:35 **Rising to the Challenge when Testing is Not Available**
~ Jeannette Thorpe, President, Barth Trust of South Africa
- 15:35 – 15:45 **The Role of BSF in the Process**
~ Michaela Damin, President, Barth Syndrome Trust (United Kingdom & Europe)
- 15:45 – 16:00 **GENES TO JEANS PANEL DISCUSSION**
(followed by Q&A's)
Moderator: Iris L. Gonzalez, Ph.D., A. I. DuPont Hospital for Children, Wilmington, DE (retired)
- 16:15 – 16:30 **BREAK (Outside of Fiesta 5)**
- Location: Fiesta 5
- 16:30 – 18:00 **KEYNOTE SPEAKER**
~ Roberto Canessa, M.D., Pediatric Cardiologist, Montevideo, Uruguay
*Combined Session with BSF Families (and children 12+)

Family Sessions

Friday, July 7, 2006

7:00 – 16:30 REGISTRATION DESK OPEN
(Outside Fiesta 5 & 6)

8:00 – 9:15 BREAKFAST (Fiesta 5) (and View Research Posters)

Location: Fiesta 7,8,9,10

9:30 – 10:15 FREQUENTLY ASKED QUESTIONS ABOUT BARTH SYNDROME
~ Richard I. Kelley, M.D., Ph.D. - Kennedy Krieger Institute, affiliate of Johns Hopkins Medical Institutions, Baltimore, MD

10:15 – 11:00 HEMATOLOGICAL ASPECTS OF BARTH SYNDROME
Chair: Colin G. Steward, M.A., B.M., B.Ch., F.R.C.P., F.R.C.P.C.H., Ph.D., Bristol Royal Hospital for Children, Bristol, UK

10:15 – 10:25 Unique Differences between Neuropenia in Barth Syndrome and other Neutropenic Disorders
~ David C. Dale, M.D., University of Washington, Seattle, WA

10:25 – 10:35 Function of Neutrophils in Barth Syndrome
~ Taco Kuijpers, M.D., Ph.D., Academic Medical Center, Amsterdam, The Netherlands

10:35 – 11:00 Hematology Panel Discussion; Q's and A's
Moderator: Dr. Colin G. Steward

11:15 – 11:25 INTRODUCTION OF BSF SCIENCE DIRECTOR
~ Katherine R. McCurdy, VP, Science & Medicine, BSF

11:25 – 11:45 FUNDING THE VISION
~ Stephen McCurdy, Chairman & Chief Financial Officer, BSF

11:45 – 13:00 LUNCH with scientists and physicians (Fiesta 5)

Location: Fiesta 7,8,9,10

13:10 - 13:30 Viewing of Discovery Health Channel Mystery Diagnosis "Blood Brothers"

13:30 – 14:30 REPORT ON RESEARCH
Chair: Miriam L. Greenberg, Ph.D., Wayne State University, Detroit MI

13:30 – 13:40 Barth Syndrome Mouse Model
~ Arnold W. Strauss, M.D., Vanderbilt Children's Hospital, Nashville, TN

13:40 – 13:50 Genetic Analysis of G4.5
~ Barry Byrne, M.D., Ph.D., Shands Children's Hospital, University School of Medicine, Gainesville, FL

13:50 – 14:00 Incidence Study for Barth Syndrome
~ Willem Kulik, Ph.D., Academic Medical Center, Amsterdam, The Netherlands

14:00 – 14:10 Drosophila Model of Barth Syndrome
~ Mindong Ren, Ph.D., New York School of Medicine, New York University, New York, NY

14:20 – 14:30 TAZ1 Function in Yeast Beyond 2002
~ Miriam L. Greenberg, Ph.D., Wayne State University, Detroit, MI

14:30 – 14:40 Apoptosis and Barth Syndrome
~ Grant Hatch, Ph.D., University of Manitoba, Winnipeg, Canada

14:40 – 14:50 Summary of BSF Funded Research: Past, Present and Future; What does all of this mean?
~ Michael Schlame, M.D., NYU School of Medicine and Cornell University, New York, NY

14:50 – 15:10 RESEARCH PANEL DISCUSSION; Q's & A's
Moderator: Miriam Greenberg, PhD, Wayne State University

Family Sessions

Friday, July 7, 2006 (cont'd)

Location: Fiesta 7,8,9,10

15:10 – 16:15 NEUROLOGICAL ASPECTS OF BARTH SYNDROME

Chair: Ariel Sherbany, M.D., Ph.D. Pediatric Neurology of Hudson Valley, Nanuet, NY

15:10 – 15:20 Neurology 101, The Central Nervous System and The Neuromuscular System: The Role of the Neurologist in Ongoing Care of Barth Syndrome

~ Ariel Sherbany, M.D., Ph.D., Pediatric Neurology of Hudson Valley, Nanuet, NY

15:30 – 15:50 Occupational and Physical Therapy: Why OT and PT are Beneficial; Techniques to Improve/Maintain Strength

~ Jeannette Van Duyne, O.T., Parrish Medical Center, Titusville, FL

~ Lynn Hancock, O.T., Brevard County School Board, Merritt Island, FL

15:50 – 16:15 Neurology Panel Discussion; Q's & A's

Moderator: Dr. Ariel Sherbany

Location: Fiesta Ballroom 5

18:30 – 23:00 BUFFET DINNER AND SOCIAL EVENT FOR ALL

Entertainment: Taylor Mason



Join us for an evening of fun and socialization for all. This gathering brings together our physicians, scientists, clinicians, and those in the medical community who have an interest in Barth syndrome with our families who live with Barth syndrome on a daily basis.

At BSF's 2004 social, we captured the true spirit of BSF's "family". As a past attendee of our 2004 social, I must say that the room was filled with such spirit! It was truly an amazing evening for all. Please come and experience the joy of BSF's family!

~ Lynda Sedefian

Entertainment will be provided by Taylor Mason, comedian, musician, ventriloquist, entertainer, and actor. DJ Daryl will once again be providing great music.

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Family Sessions

Saturday, July 8, 2006

Location: Coronado J

8:15 – 9:30 BREAKFAST

Location: Yucatan 1 & 2

9:45 – 12:00 DAY-TO-DAY ASPECTS WITH A CHRONICALLY ILL CHILD

Chair: John Reiss, Ph.D., Institute of Child Health Policy, University of Florida, Gainesville, FL

9:45 – 10:45 THE CHILDREN

9:45 – 10:00 **The Role of the Clinician as a Member of the Team**
~ Patricia Blanco, M.D., University Pediatrics, Sarasota, FL

10:00 – 10:10 **The Role of the Parent as a Member of the Team**
~ Stephanie Radar, R.N., Parent of Barth Individual

10:10 – 10:30 **The Psychology of A Chronically Ill Child**
~ Eric Storch, Ph.D., University of Florida, Gainesville, FL

10:30 – 10:45 **The Dynamics of Having A Chronically Ill Brother**
~ Chrisie Petersen, B.S.W., Achieve Tampa Bay, Tampa Bay, FL

10:45 – 11:05 THE PARENTS

10:45 – 10:55 **A Mother's Perspective; You Have To Go With Your "Gut Instinct"**
~ Lynda Sedefian, Parent of Barth Individuals

10:55 – 11:05 **A Father's Perspective; I Can't Fix This Problem**
~ Scott Oldewage, Parent Barth Individual

Location: Yucatan 1 & 2

11:05 – 11:40 EXTENDED FAMILY AND FRIENDS

11:05 – 11:15 **A Grandparent's Perspective**
~ Terry Dannels, Grandparent of Barth Individual

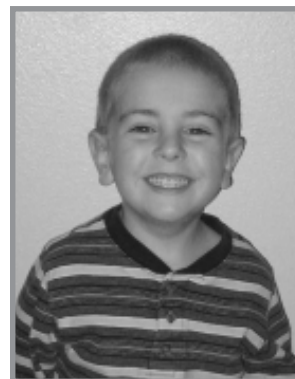
11:15 – 11:25 **An Extended Family Member's Perspective**
~ Linda Croxton, ARNP, Aunt of Barth Individual

11:25 – 11:35 **Flying Without Instruments**
~ John G. Reiss, Ph.D., Institute of Child Health Policy, University of Florida, Gainesville, FL

11:35 – 12:00 **Chronically Ill Child Panel Discussion: Q&A's**
~ John G. Reiss, Ph.D., Institute of Child Health Policy, University of Florida, Gainesville, FL

Location: Coronado J

12:00 – 13:15 LUNCH



Family Breakout Sessions

Saturday, July 8, 2006 (Location: Fiesta 7, 8, 9 & 10)

EARLY YEARS: BIRTH TO FOUR

Chair: Michelle Telles, Parent of Barth Individual

**13:30 – 14:00 Psychology: Ready or Not
Welcome Barth Syndrome**
~ Jill Storch, M.S.Ed.

**14:00 – 14:45 Healthcare Concerns: Dealing
with Frequent Infections and
not Living at the Pediatrician's
Office**
~ Patricia Blanco, M.D.

14:45 – 15:45 Day to Day Concerns: Nutrition; Early Intervention
~ Rhonda Avery, R.D., L.D./N., C.D.E.



HONEYMOON PHASE: FIVE TO ELEVEN YEARS OF AGE

Chair: Jan Kugelmann, Parent of Barth Individual

**13:30 – 14:00 Psychology: Noticing the
Differences**
~ Lisa Merlo, Ph.D.

**14:00 – 14:45 Educational Concerns: Making
the Most of Your Child's Education**
~ Jon Rosenshine, M.A., M.Ed.

**14:45 – 15:45 Health and Development: Raising a Well-
Balanced Child With an Unpredictable Disorder**
~ John Nackashi, M.D.



BTHS RESURFACING:

TWELVE TO FIFTEEN YEARS OF AGE

Chair: Lynda Sedefian, Parent of Barth Individuals

**13:30 – 14:00 Psychology: The Balance
Between Independence and
Negligence**
~ Eric Storch, Ph.D.

**14:00 – 14:45 Educational Concerns: Meeting Greater Demands
in School with Decreased Stamina**
~ Eileen Juico, M.A., M.Ed.

**14:45 – 15:45 Health and Development: Barth Syndrome During
the Adolescent Years**
~ Patricia Blanco, M.D.



INDEPENDENCE: SIXTEEN AND OLDER

Chair: Chris Hope, Parent of Barth Individual

**13:30 – 14:00 Psychology: New Challenges,
Different Concerns**
~ Lauren Stutts, B.S.

**14:00 – 14:45 Educational Concerns: The
Fine Line of Balance
Between Dependence and
Independence for High School/College -Aged**
~ Jaclyn M. Butera, M.S.W., C.S.W, M.S.Ed.

**14:45 – 15:45 Health and Development: Transitions into an
Adult Healthcare System that is Unprepared to
Meet the Challenges and Achieve an
Independent Life**
~ John Reiss, Ph.D.



16:00 - 17:00 CLOSING CEREMONY (Location: Coronado J)

Those With Barth Syndrome (Ages 8+)

Monday July 3, 2006

Location: Yucatan 2 & 3

18:30 – 21:00 KIDS' MOVIE NIGHT (All Ages)
(*Children under the age of 3 must be accompanied
by an adult)

Tuesday, July 4, 2006

Location: Fiesta 5 & 6

7:00 – 17:00 pm CLINICS/CONSULTS

LUNCH & DINNER ON YOUR OWN

Wednesday, July 5, 2006

Location: Fiesta 5 & 6

7:00 – 17:00 pm CLINICS/CONSULTS

LUNCH & DINNER ON YOUR OWN

Location: Durango 1 & 2

19:00 – 21:30 CHAPERONED YOUTH GATHERING -
Entertainment provided by Renee Adams
~ Dance, games, etc! Come and enjoy some fun
with your friends!!

Those Who Have Brothers with Barth Syndrome (Ages 8+)

Monday July 3, 2006

Location: Yucatan 2 & 3

18:30 – 21:00 KIDS' MOVIE NIGHT (All Ages)
(*Children under the age of 3 must be accompanied
by an adult)

Wednesday, July 5, 2006

Location: Durango 1 & 2

19:00 – 21:30 CHAPERONED YOUTH GATHERING -
Entertainment provided by Renee Adams
~ Dance, games, etc! Come and enjoy some fun
with your friends!!

Holman

AUTOMOTIVE

Those With Barth Syndrome (Ages 8+)

Thursday, July 6, 2006

8:15 – 9:30 BREAKFAST (Location: Fiesta 5)

Location: Coronado T

9:45 – 10:45 Group Connect/Ice-breakers (ALL)
Introduction to Digital Cameras & Photoshop -
Paparazzi in the Making
*Moderators: B.J. Develle; Jon Rosenshine, M.A.,
M.Ed.; Jaclyn Butera, M.S.W., C.S.W., M.Ed.*

10:45 – 11:00 Kick back, Relax, Chill Out

11:00 - 12:00 **Bullying (Ages 8-15)**
~ Eric A. Storch, Ph.D., University of Florida
Moderators: B.J. Develle/Jon Rosenshine, M.A., M.Ed.

Location: Executive Suite

11:00 - 12:00 **Life with a Heart Condition or ICD: What's Normal
About It? (Ages 16 and older)**
~ Jaclyn Butera, M.S.W., C.S.W., M.Ed.
~ Randall Bryant, M.D.

12:00 – 13:15 **LUNCH (Location: Fiesta 5)**

13:30 – 14:15 **GROUP PHOTOS (Amanda) (Location: Coronado T)**

14:15 - 15:00 Photo 101
~ B.J. Develle & Jon Rosenshine, M.A., M.Ed.

15:00 - 16:00 **SPEED CONNECTING (ALL)**

16:00 – 16:30 Time to chill, thrill, relax, kick back and wind down
~ B.J. Develle & Jon Rosenshine, M.A., M.Ed.

Location: Fiesta 5

16:30 – 18:00 **KEYNOTE SPEAKER (Ages 12+)**
~ Roberto Cannessa, M.D., Montevideo, Uruguay
Escorts: Jon Rosenshine and Jaclyn Butera

Location: Coronado T

16:30 – 18:00 **Games & Activities (for those ages 12+ not
attending Keynote Address)**
~ B.J. Develle

Those Who Have Brothers with Barth Syndrome (Ages 8+)

Thursday, July 6, 2006

8:15 – 9:30 BREAKFAST (Location: Fiesta 5)

Location: Coronado R & S

9:45 – 10:00 **INTRODUCTION OF SIBSHOPS**
Rules and theme for the sibling sessions - "Teamwork"

10:15 – 11:00 **Get to Know You - Games**

11:00 – 11:45 Session with Amanda Clark (Photographer)

11:45 – 12:00 "Let the Games Begin"

Location: Fiesta 5

12:00 – 13:15 **LUNCH**

Location: Coronado R & S

13:15 – 13:30 Survivor "Coronado Springs" Design of Team Flag

13:30 – 15:00 Team Challenges

15:00 – 15:30 Survivor Food Wheel

15:30 – 16:00 Team Work Games

16:00 – 16:30 Prepping for Dr. Canessa's Keynote Address
1) Children not attending keynote speech
will go to childcare
2) Open discussion about the bravery of Dr.
Canessa and the importance of respecting his
ordeal

Those With Barth Syndrome (Ages 8+)

Friday, July 7, 2006

8:00 – 9:15 BREAKFAST (Location: Fiesta 5)

Location: All Sessions in Coronado T unless otherwise specified

9:30 – 11:45 Fun with B.J. & Jon! (Ages 8-11)
~ B.J. Develle & Jon Rosenshine, MA, MEd

Location: Executive Suite

9:30 - 10:30 Team Building and Group Dynamics in Crisis
Situations: A Discussion of Dr. Roberto Canessa's
speech (Ages 12+)
Moderator: Jaclyn Butera, MSW, CSW, MEd

10:30 - 10:45 Hang out, take 5, loaf around, interact

10:45 - 11:45 Report on Barth Research
~ Miriam L. Greenberg, PhD
Moderator: Jaclyn Butera, MSW, CSW, MEd

11:45 – 13:00 LUNCH (w/ All) (Location: Fiesta 5)

13:15 – 14:15 Jeans to Genes - Genetics of Barth Syndrome
~ Iris L. Gonzalez, PhD
Moderators: B.J. Develle & Jon Rosenshine, MA, MEd

14:15 - 14:45 Paparazzi 101 (Digital cameras; Photoshop)

14:45 - 16:00 Speed connecting (ALL)

18:30 - 21:00 SOCIAL FOR ALL (Location: Fiesta 5)

Saturday, July 8, 2006

8:15 – 9:30 BREAKFAST (Location: Coronado J)

Location: Coronado T

9:45 – 10:45 Work on projects/ DVD Interviews (All youth)

11:00 - 12:00 Self-defense Demonstration (All youth)

12:00 – 13:15 LUNCH (Fiesta 5)

13:30 – 16:00 GETTING READY FOR FINAL PRESENTATION
(All youth)

16:00 – 17:00 CLOSING (Final Presentation) (Location: Coronado J)

Those Who Have Brothers with Barth Syndrome (Ages 8+)

Friday, July 7, 2006

8:00 – 9:15 BREAKFAST (Location: Fiesta 5)

Location: All Sessions in Coronado R & S unless otherwise specified

9:15 – 9:30 Regroup meeting into teams

9:30 – 9:45 RULES OF HUNT

9:45 – 11:00 SURVIVOR TEAM SCAVENGER HUNT

11:00 – 11:15 Sibling Q & A Session
Moderator: Alanna Layton

11:15 – 11:45 Discussion about Dr. Canessa's presentation (Siblings
who attended Dr. Canessa's keynote address)

11:15 – 11:45 "Dear Aunt Blabby" (Siblings who did not attend Dr.
Canessa's speech)

11:45 – 13:00 COMBINED LUNCH (Location: Fiesta 5)

13:00 – 14:30 Team Activity

14:30 – 15:30 Jeopardy

15:30 – 16:30 Wind down

18:00 – 21:00 BUFFET DINNER & SOCIAL FOR ALL (Fiesta 5)

Saturday, July 8, 2006

8:15 – 9:30 BREAKFAST (Location: Fiesta 5)

9:45 – 10:45 Arts and crafts

11:00 – 12:00 Self-defense demonstration

12:00 – 13:15 LUNCH (Location: Coronado J)

Location: Coronado R & S

13:30 – 15:15 Work on presentation

15:15 – 15:45 Final thoughts and observations

16:00 – 17:00 CLOSING (Final Presentation) (Coronado J)

Conference at a Glance

	Scientific and Medical Sessions	Family Sessions	Youth Sessions		
			A. Those who have Barth syndrome Ages 3-15	B. Those who have Barth syndrome Ages 16+	C. Those who have a brother with Barth syndrome Ages 5+
Monday July 3, 2006		<i>South Registration Counter</i> 15:00-21:00 Registration Desk			
		<i>Monterey 1-3</i> 18:30-21:00 Family Reception	<i>Yucatan 2 & 3</i> 18:30-21:00 Movie Night (All ages) <small>*children under 3 need to be accompanied by adult</small>	<i>Yucatan 2 & 3</i> 18:30-21:00 Movie Night (All ages) <small>*children under 3 need to be accompanied by adult</small>	<i>Yucatan 2 & 3</i> 18:00-21:00 Movie Night (All ages) <small>*children under 3 need to be accompanied by adult</small>
Tuesday July 4, 2006		<i>South Registration Counter</i> 7:00-17:00 Registration Desk			
		<i>Fiesta 5 & 6</i> 7:00-17:00 Clinics/Consults	<i>Fiesta 5 & 6</i> 7:00-17:00 Clinics/Consults	<i>Fiesta 5 & 6</i> 7:00-17:00 Clinics/Consults	
Wednesday July 5, 2006	<i>South Registration Counter</i> 16:00 - 20:00 Registration	<i>South Registration Counter</i> 7:00-20:00 Registration Desk			
		<i>Fiesta 5 & 6</i> 7:00-17:00 Clinics/Consults	<i>Fiesta 5 & 6</i> 7:00-17:00 Clinics/Consults	<i>Fiesta 5 & 6</i> 7:00-17:00 Clinics/Consults	
		<i>Coronado R-T</i> 19:00-21:00 BSF Family Meeting	<i>Durango 1 & 2</i> 19:00-21:00 Youth Dance Party <small>*children under 3 need to be accompanied by adult</small>	<i>Durango 1 & 2</i> 19:00-21:00 Youth Dance Party <small>*children under 3 need to be accompanied by adult</small>	<i>Durango 1 & 2</i> 19:00-21:00 Youth Dance Party <small>*children under 3 need to be accompanied by adult</small>
Thursday July 6, 2006	<i>South Registration Counter</i> 7:00-16:00 Registration Desk Open	<i>South Registration Counter</i> 7:00-16:00 Registration Desk Open			
	<i>Fiesta 1 - 3</i> CONTINENTAL BREAKFAST	<i>Fiesta 5</i> 8:15-9:30 BREAKFAST	<i>Fiesta 5</i> 8:15-9:30 BREAKFAST	<i>Fiesta 5</i> 8:15-9:30 BREAKFAST	<i>Fiesta 5</i> 8:15-9:30 BREAKFAST
	<i>Fiesta 1 - 3</i> 8:00-8:15 Introduction & Overview 8:15-12:40 Gene Products and Biochemistry of BTHS (10:30 - 10:45 Break)	<i>Fiesta 7,8,9,10</i> 9:45-10:00 Opening Remarks 10:00-12:00 Cardiac Aspects of Barth Syndrome	<i>Coronado T</i> 9:45-10:45 Group Connect Paparazzi in the Making <i>Coronado T</i> 11:00-12:00 Bullying - Dr. Eric Storch	<i>Coronado T</i> 9:45-10:45 Group Connect Paparazzi in the Making <i>Executive Suite</i> 11:00-12:00 Life with a heart condition or ICD. What's normal about that? - Dr. Bryant	<i>Coronado R-S</i> 9:45-10:00 Introduction to SibShops 10:00-11:00 Get to Know You 11:00-11:45 Photo Session w/Amanda Clark 11:45-12:00 Let the Games Begin
	<i>Coronado A-C</i> 12:45- 13:30 LUNCH	<i>Fiesta 5</i> 12:00-13:15 LUNCH	<i>Fiesta 5</i> 12:00-13:15 LUNCH	<i>Fiesta 5</i> 12:00-13:15 LUNCH	<i>Fiesta 5</i> 12:00-13:15 LUNCH
	<i>Fiesta 1 - 3</i> 13:35-16:15 New Frontiers of BTHS Science	<i>Fiesta 7,8,9,10</i> 13:30-14:45 Barth Syndrome Medical Database & Biorepository 14:45-16:00 Jeans to Genes - Genetics of Barth Syndrome	<i>Coronado T</i> 13:30-14:10 Group Photos 14:15-15:00 Speed Connecting 16:00-16:30 Chill Out with B.J. & Jon 16:30-18:00 Games & Activities with B.J. for those not attending keynote address	<i>Coronado T</i> 13:30-14:10 Group Photos 14:15-15:00 Speed Connecting 16:00-16:30 Chill Out with B.J. & Jon 16:30-18:00 Games & Activities with B.J. for those not attending keynote address	<i>Coronado R-S</i> 13:15-13:30 Survivor 13:30-15:00 Team Challenges 15:00-15:30 Survivor Food Wheel 15:30-16:00 Team Work - Games 16:00-18:00 Preparing for Dr. Canessa (Games w/Chrisie for those not attending keynote address)
	<i>Fiesta 5 Foyer</i> 16:15 - 16:30 Break	<i>Fiesta 5 Foyer</i> 16:15 - 16:30 Break			
	<i>Fiesta 5</i> 16:30 - 18:00 Keynote Speaker 18:00-20:00 Poster Session	<i>Fiesta 5</i> 16:30-18:00pm Keynote Speaker	<i>Fiesta 5</i> 16:30-18:00pm Keynote Speaker <small>*Recommended for Ages 12 and up</small>	<i>Fiesta 5</i> 16:30-18:00pm Keynote Speaker <small>*Recommended for Ages 12 and up</small>	<i>Fiesta 5</i> 16:30-18:00 Keynote Speaker <small>*Recommended for Ages 12 and up</small>

Conference at a Glance

	Scientific and Medical Sessions	Family Sessions	Youth Sessions		
			A. Those who have Barth syndrome Ages 8-11	B. Those who have Barth syndrome Ages 12+	C. Those who have a brother with Barth syndrome
	South Registration Counter Outside Fiesta 5 & 6	South Registration Counter Outside Fiesta 5 & 6			
Friday July 7, 2006	7:00-17:00 Registration Desk Open	7:00-17:00 Registration Desk Open			
	<i>Fiesta 1 - 3</i>	<i>Fiesta 5</i>	<i>Fiesta 5</i>	<i>Fiesta 5</i>	<i>Fiesta 5</i>
	7:30-8:00 COFFEE & DANISH	8:00-9:15 BREAKFAST	8:00-9:15 BREAKFAST	8:00-9:15 BREAKFAST	8:00-9:15 BREAKFAST
	<i>Fiesta 1 - 3</i>	<i>Fiesta 7,8,9,10</i>	<i>Coronado T</i>	<i>Executive Suite</i>	<i>Coronado R-S</i>
	8:00-12:00 Cardiac Issues of BTHS (10:15 -10:30 Break)	9:30-10:15 Frequently Asked Questions 10:15-11:45 Hematology	9:30-11:45 Fun with B.J. & Jon	9:30-10:30 Team Building 10:30-10:45 Hang, Loaf, Take 5 10:30-11:45 Report on Research	9:30-11:00 Regroup and prepare for "Survivor Team Scavenger Hunt" 11:00-11:45 Dear Aunt Babby
	<i>Fiesta 5</i>	<i>Fiesta 5</i>	<i>Fiesta 5</i>	<i>Fiesta 5</i>	<i>Fiesta 5</i>
	12:00-13:00 LUNCH w/ Families	11:45-13:00 LUNCH w/ Physicians	11:45-13:00 LUNCH w/ Physicians	11:45-13:00 LUNCH w/ Physicians	11:45-13:00 LUNCH w/ Physicians
	<i>Fiesta 1 - 3</i>	<i>Fiesta 7,8,9,10</i>	<i>Coronado T</i>	<i>Coronado T</i>	<i>Coronado R-S</i>
	13:05-16:30 Hematological Aspects of BTHS (15:40 -16:00 Break) 16:00-16:30 Barth Syndrome Medical Database and Biorepository 16:30-17:00 Meeting Summary and Thoughts for the Future 17:00-18:00 FREE TIME	13:05-13:30 Mystery Diagnosis 13:30-14:30 Report on Research 15:10-16:15 Neurology	13:15-14:15 Jeans to Genes - Genetics of Barth Syndrome 14:15-14:45 Paparazzi 101 14:45-16:15 Speed Connecting	13:15-14:15 Jeans to Genes - Genetics of Barth Syndrome 14:15-14:45 Paparazzi 101 14:45-16:15 Speed Connecting	13:15-14:30 Team Activity 14:30 -15:30 Jeopardy 15:30 - 16:15 Games
	<i>Fiesta 5</i>	<i>Fiesta 5</i>	<i>Fiesta 5</i>	<i>Fiesta 5</i>	<i>Fiesta 5</i>
18:30-23:00 SOCIAL EVENT - ALL	18:30-23:00 SOCIAL EVENT - ALL	18:30-23:00 SOCIAL EVENT - ALL	18:30-23:00 SOCIAL EVENT - ALL	18:30-23:00 SOCIAL EVENT - ALL	
Saturday July 8, 2006	South Registration Counter Outside Fiesta 5 & 6	South Registration Counter Outside Fiesta 5 & 6			
	7:00-16:00 Registration Desk Open	7:00-16:00 Registration Desk Open			
	<i>Coronado E-G</i>	<i>Coronado J</i>	<i>Coronado J</i>	<i>Coronado J</i>	<i>Coronado J</i>
	8:00-10:00 BSF's Scientific and Medical Advisory Board Meeting (breakfast served)	8:15-9:30 BREAKFAST	8:15-9:30 BREAKFAST	8:15-9:30 BREAKFAST	8:15-9:30 BREAKFAST
	8:00-10:00 Free time for Non-SMAB	<i>Yucatan 1 & 2</i>	<i>Coronado T</i>	<i>Coronado T</i>	<i>Coronado R-S</i>
		9:45-12:00 Day-to-day aspects with a chronically ill child	9:45-10:45 Projects/DVD Interviews 11:00-12:00 Self-Defense Demo	9:45-10:45 Projects/DVD Interviews 11:00-12:00 Self-Defense Demo	9:45-10:45 Arts & Crafts 11:00-12:00 Self Defense Demo
	<i>Coronado E-G</i>	<i>Coronado J</i>	<i>Coronado J</i>	<i>Coronado J</i>	<i>Coronado J</i>
	10:00-15:45 Working Sessions (lunch served)	12:00-13:15 LUNCH	12:00-13:15 LUNCH	12:00-13:15 LUNCH	12:00-13:15 LUNCH
		<i>Fiesta 7,8,9,10</i>	<i>Coronado T</i>	<i>Coronado T</i>	<i>Coronado R-S</i>
	13:30-16:00 Family Breakout Sessions	13:30-16:00 Finale Preparation/Final Thoughts	13:30-16:00 Finale Preparation/Final Thoughts	13:30-16:00 Finale Preparation/Final Thoughts	
<i>Coronado J</i>	<i>Coronado J</i>	<i>Coronado J</i>	<i>Coronado J</i>	<i>Coronado J</i>	
16:00-17:00 Closing Sessions w/families	16:00-17:00 Closing Sessions w/youth & physicians	16:00-17:00 CLOSING SESSION	16:00-17:00 CLOSING SESSION	16:00-17:00 CLOSING SESSION	



Rhonda Avery, R.D., L.D./N., C.D.E. — Clinical Dietician – Nutritional Education Specialist, Watson Clinic LLP, Clinical Dietitian, Lakeland Regional Medical Center, Lakeland, Florida

Ms. Avery provides inpatient and outpatient nutritional assessments and counseling for disease prevention and management. Her primary emphasis is on diabetes, cardiovascular disease and obesity management. She has developed educational and community programs to include cooking demonstrations, pediatric weight management program, cardiac rehabilitation nutrition classes and diabetes education.



Francois P. Bernier, M.D., F.R.C.P.C., F.C.C.M.G. — Associate Professor in the Department of Medical Genetics, University of Calgary, Calgary, Alberta, Canada

Dr. Bernier is an Associate Professor in the Department of Medical Genetics at the University of Calgary, Canada. He is also Clinical Director of the R.B. Lowry Genetics Unit, which serves Southern Alberta, Canada. He obtained his MD through the University of Manitoba and completed his residency training in Medical Genetics at the University of Calgary. He is a Fellow of the Canadian College of Medical Genetics and a member of the American Society of Human Genetics. Dr. Bernier is the recipient of numerous awards for his teaching in the Faculty of Medicine. His research interests include the role of the prenatal environment on child health, fetal development and a genetic (Barth-like) disorder in the Hutterite community.



Patricia Juarez Blanco, M.D., F.A.A.P. — University Pediatrics, Sarasota, FL

Dr. Blanco currently holds a Clinical Faculty position at both the University of South Florida, Department of Pediatrics and Florida State University College of Medicine. She maintains a solo pediatric practice in Sarasota, FL. She is a Diplomat of the American Board of Pediatrics and a Fellow of the American Academy of Pediatrics. She has a special interest in community pediatrics, participating actively in this field for the past 14 years. She is the Medical Foster Care Director and Assistant Medical Director for Children's Medical Services serving Charlotte, DeSoto, Manatee and Sarasota Counties. Dr. Blanco has been an AAP CATCH facilitator as well as an active participant in the Medical Home Project on the national and state levels.



Valerie "Shelley" M. Bowen — President, Barth Syndrome Foundation, Inc., Perry, FL (Headquarters)

Mrs. Bowen serves as the president of the Barth Syndrome Foundation as well as being a founding member of the organization. She is the proud mother of Alanna, who completed her graduate studies at the University of South Carolina in May of 2005; Michael, age 19, currently a high school senior; and Evan, who passed away in 1990. Through Shelley's personal experiences of having two children with Barth syndrome she is committed to the fundamental goals of the Barth Syndrome Foundation.



Karla R. (Schultz) Bowles, Ph.D., F.A.C.M.G. — Assistant Professor, Laboratory Director, John Welsch Cardiovascular Diagnostic Laboratory, Department of Pediatrics, Section of Cardiology, Baylor College of Medicine, Houston, TX

Dr. Bowles' major interests include the development and implementation of diagnostic tests for acquired and genetic forms of cardiac disease. Currently, the laboratory is offering screening for viruses associated with myocarditis and cardiac transplant rejection, as well as intrauterine infections. Eleven genetic tests are offered that screen for diseases (including Barth syndrome) that result in dilated cardiomyopathy, congenital heart disease, and sudden cardiac death. This test menu is constantly expanding as our knowledge of the genetics of cardiomyopathy increases. In addition, research studies are being performed in order to broaden our knowledge of the underlying mechanisms of dilated cardiomyopathy, Barth syndrome, hypertrophic cardiomyopathy and other genetic forms of heart disease.



Randall M. Bryant, M.D. — 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

Dr. Bryant's specialties include pediatric cardiology and pediatric medicine. He 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.



Jaclyn M. Butera, M.S.W., C.S.W., M.Ed. — Counselor and Dean, Rye Country Day School, Rye, NY

Ms. Butera is a certified clinical social worker and school administrator. She has worked in independent school education for nine years, and in her present position at Rye Country Day School, Ms. Butera is the Dean of Student Life; she oversees the Peer Leadership program and she serves as counselor-at-large for a high school community of 350 student and 50 faculty members. She also has seven years' experience in family social work for Westchester County and served as the youth advocate in Rye from 1992 to 1995. In conjunction with the Learning Specialist at Rye Country Day School, she has offered support to students who are struggling with long term illnesses. Her life, both personally and professionally, has been deeply impacted by a student with Barth syndrome and her involvement with the Foundation.



Barry J. Byrne, M.D., Ph.D. — Cardiology Director, Department of Pediatrics, Shands Children's Hospital, University School of Medicine, Gainesville, FL; Professor & Associate Chair of Pediatrics, Molecular Genetics & Microbiology; Director, Powell Gene Therapy Center, University of Florida, Gainesville, FL; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc.

Dr. Byrne is a pediatric cardiologist in the Departments of Pediatrics and Molecular Genetics and Microbiology at the University of Florida, 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 Assoc., Muscular Dystrophy Association, and the National Institutes of Health (NHLBI, NIDDK, and NCRR). Saving lives through education, advances in treatment and pursuit of a cure for Barth syndrome



Roberto Canessa, M.D. — Pediatric Cardiologist, Montevideo, Uruguay

Dr. Canessa is a renowned cardiologist and has been awarded three national distinctions in Medicine in Uruguay. An outstanding rugby player who represented Uruguay, Roberto Canessa still holds the record of Top Try Scorer in Uruguay. In 1972, together with a delegation of his rugby club Old Christians, their plane crashed in the Andes on their way to Chile. At 3,500 meters above sea level and with temperatures below freezing, without any source of food and no contact with civilization, after 72 days, only 16 of the 45 passengers survived and are able to tell the story. The dynamics of human groups in situations of crisis has given way to many theories about leadership, team search of solutions, optimization of the qualities of each individual in a team. However, the Andes experience is a unique real case where a human group encountered an extreme situation, where common people facing incredible situations, found admirable solutions.



Sharon R. Chapman, R.V.S. — Pediatric Cardiac Sonographer, Shands Teaching Hospital, University of Florida, Gainesville, Florida and Adjunct Instructor, Vascular Technology, Santa Fe Community College, Gainesville

Ms. Chapman's current responsibilities include, patient care and diagnostic echocardiograms and stress echocardiograms on neonates, adolescents and adults with congenital heart defects. Her career also includes Vascular Technologist and Research Sonographer. She has undertaken all aspects of vascular testing utilizing multiple modalities, providing interpretations and correlating test results for QA reports. She has also aided in developing research protocols.

Ms Chapman holds an Associate of Science Degree in Cardiopulmonary Technology, 1998, from Santa Fe Community College, Gainesville, Florida.



Linda Croxton, M.S.N., A.R.N.P., C.D.E. — Nurse specialist, Watson Clinic, LLP, Lakeland, FL

Mrs. Croxton presently performs outpatient diabetes education counseling and classroom instruction. She is in collaboration with a multidisciplinary team in the development of diabetes curriculum and educational material.

As Shelley Bowen's aunt, Linda has witnessed firsthand the challenges of a disorder without a diagnosis as well as the day-to-day challenges of caring for two children with a chronic, life-threatening disorder. Linda has attended each of the BSF conferences. She has been inspired by the many families she has met over the years at these events. She strongly believes in better health outcomes when the family is informed and they are also the natural advocates for their children and in the case of a complex disorder such as Barth syndrome.



David C. Dale, M.D. — Professor of Medicine, University of Washington Medical Center, Seattle, WA; Board of Regents and President-Elect, American College of Physicians and Editor-in-Chief of textbook Scientific American® Medicine

Dr. Dale trained in Internal Medicine at the Massachusetts General Hospital Boston and the University of Washington Medical Center, Seattle and previously served as Senior Investigator, Laboratory of Clinical Investigation, National Institute of Allergy and Infectious Diseases, NIH, Bethesda (1972 - 1974) and Associate Professor of Medicine, University of Washington, Seattle, WA (1974 - 1978). During six years at the National Institutes of Health, 1968 - 1974, he developed a lasting interest in research on inflammation, neutrophils, and the clinical problem of neutropenia. Dr. Dale is actively involved in teaching and patient care at the University of Washington Medical Center.



Michaela Damin — Founding Member and Chairperson, Barth Syndrome Trust - United Kingdom and Europe

Mrs. Damin has been the inspiration and driving force behind the Barth Syndrome Trust in the United Kingdom. She lives in Hampshire, England with her husband, Marco, and sons, Nicholas and Matthew. The family left South Africa to find treatment for Nicholas, who was later diagnosed with Barth syndrome.

Through Michaela's vision, energy and commitment, the Barth Syndrome Trust has grown steadily and become increasingly well known to the medical community within the United Kingdom. Michaela has attracted and motivated a number of volunteers to help with the programs of the Trust.



Terry Dannels, R.N., M.P.H. — Infection Control Professional and Registered Nurse

Ms. Dannels has a masters in Public Health and currently runs her own consulting firm. Terry and her husband, Dick, lost two sons to Barth syndrome in 1963 and 1968, respectively. They are extremely grateful for the existence of BSF and for the families and scientists who strive to learn how to treat and eventually cure this syndrome. The Dannels have attended the BSF conferences since the first one in Baltimore and are honored to have a part in this present one.

Terry loves and enjoys her four grandchildren, three girls: Kelsey, Olivia, Isabella and one boy, Jack Higgins who has Barth syndrome.



Jane Day, Ph.D. — Clinical Associate Professor and Assistant Chair of Physical Therapy at the University of Florida, Gainesville, FL

Dr. Day is also the Director of Education for the department and is the administrator for the entry-level Doctor of Physical Therapy (DPT) program. She has over 35 years of experience in physical therapy with extensive experience as both a clinician and an educator. Her clinical experiences have been in a variety of settings and her area of expertise is pediatrics. She is currently one of the investigators looking at skeletal muscle strength in boys with Barth syndrome. She is a past member of the Commission on Accreditation in Physical Therapy Education and of other appointed committees related to education.



Bruce Justin (B.J.) Develle — Mental Health Care Services Professional

Bruce (B.J.) provides case management services to children with severe mental health needs. Typically the problems are in the areas of brain injuries, physical and sexual abuse, mood disorders, Juvenile Justice involvement, Foster care, drug exposure, suicidal and homicidal attempts and psychiatric residential placement. Bruce typically provides guidance, counseling, crisis intervention and mentorship to the children and their families, and advocates for the children. Previously, he supervised group homes for teenage boys and girls, respectively.

Bruce graduated with degrees in Religion and Child Development from Florida State University in 2002.



Lynn Elwood — President, The Barth Syndrome Foundation of Canada

Mrs. Elwood is a founding board member of the Barth Syndrome Foundation of Canada and is passionately involved with the Barth Syndrome Foundation's initiatives, including the Medical Database/Biorepository and leading the Technology program. Lynn, her Barth son Adam (16), husband Rick, and unaffected son Justin (9) live in Ajax, Ontario. Lynn's other activities include a full-time position as Director of Research and Development for Hummingbird Inc. She also holds two black belts in martial arts and produces her cottage association website and newsletter.



Tal Geva, M.D. — Senior Associate and Chief of the Noninvasive Division, Department of Cardiology, Children's Hospital Boston, Boston, MA

Dr. Geva is also an Associate Professor of Pediatrics at Harvard Medical School. He devotes most of his clinical and research efforts to noninvasive diagnostic imaging of congenital heart disease by echocardiography and MRI. His research has focused on the application of MRI to anatomic and functional imaging in congenital heart disease and on development of noninvasive methods to predict outcome based on morphometric and functional data.



Iris L. Gonzalez, Ph.D. — Molecular Diagnostics Laboratory, Alfred I. DuPont Hospital for Children, Wilmington, DE; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc.

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, however, for writing a layman's guide to genetics that has been extremely valuable to BSF families and others.



Miriam L. Greenberg, Ph.D. — 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.

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 lab 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.



Lynn Hancock, O.T. — Occupational Therapist, Brevard County School Board, Merrit Island, FL

Ms. Hancock is an occupational therapist who currently works for the Brevard County Schools. She graduated in 1983 from Utica College of Syracuse University with a Bachelors of Science in Occupational Therapy. Lynn has devoted most of her career to pediatrics. She works closely with educators and parents, but her greatest enjoyment is trying to meet the needs of the children she serves.



Grant M. Hatch, Ph.D. — Director of the Lipid Lipoprotein and Atherosclerosis Research Group, University of Manitoba; 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.

Dr. Hatch's research interests focus on metabolism and pharmacological modulation of phospholipids (including cardiolipin) in the mammalian heart and cells in culture. He has published numerous papers on these topics.



Christiane Hope — Co-Chair, Family Services, Barth Syndrome Foundation, Inc.; Secretary, Barth Syndrome Foundation of Canada

Mrs. Hope is the mother of four (two who have Barth syndrome—one deceased, and one now a young man). She has been with BSF since its inception, and is the co-chair of Family Services and Treasurer for BSF of Canada. Chris lives in Georgetown, Ontario with her husband Michael and two youngest children, Robert who has Barth syndrome and his twin Andrew.



Robert E. Jensen, Ph.D. — Professor, Cell Biology & Anatomy, The Johns Hopkins School of Medicine

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 mitochondrial disorders, including Barth syndrome.



Eileen Q. Juico, M.A., M.Ed. — Director of Support Services, Rye Country Day School, Rye, NY

Ms. Juico has taught in both public and private schools for the past 11 years providing additional academic support to individuals with a variety of needs. As a learning specialist at RCDS, she has worked closely with the upper school counselor helping students with physical, emotional, and learning challenges. Ms. Juico is an educational consultant for BSF, and she became involved with the group through her friendship with a young man with Barth syndrome who attended RCDS. This year Ms. Juico's family will join her at the conference; her mother-in-law, Mary Knauer, her husband, Bill Knauer, and their daughter, Emiliana Quinn Knauer, who will be celebrating her first birthday on July 4th!



Richard I. Kelley, M.D., Ph.D. — Professor of Pediatrics, John 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, The Barth Syndrome Foundation Scientific and Medical Advisory Board

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 cofounder 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.



Rebecca L. Kern, M.G.C. — Genetic Counselor, Department of Neurogenetics, Division of Metabolism, Kennedy Krieger Institute, Baltimore, MD

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 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.



Jan Kugelmann — Conference Chair; Co-Chair, Awareness, Barth Syndrome Foundation, Inc.

Mrs. Kugelmann resides in Merritt Island, Florida with her husband of 23 years, Steve. They have two children, Elizabeth Lee, 13 and Robert Jack (R.J.) 8, who has Barth syndrome. She received her BA from the University of Central Florida and spent many years in the legal profession and working at Kennedy Space Center before pursuing her most challenging position, full-time mom. She has been actively involved in the Barth Syndrome Foundation since R.J.'s diagnosis in 2000.



Stephen Kugelmann — Vice President, Awareness, Barth Syndrome Foundation, Inc.

Mr. Kugelmann has a BS in mechanical engineering from the University of Central Florida and is employed by United Space Alliance at the Kennedy Space Center as a Design Engineering Manager for the Space Shuttle program. He has been married to Jan for 23 years and has two children, Elizabeth Lee, 13 and Robert Jack (R.J.), 8, who has Barth syndrome. He currently serves as Vice President of Awareness for the Barth Syndrome Foundation and devotes his spare time to ensuring the goals of the foundation are successful.



Taco Kuijpers, M.D., Ph.D. — Academic Medical Center, Amsterdam, The Netherlands

Dr. Kuijpers is professor in Pediatric Immunology and is heading the Department of Pediatric Hematology, Immunology and Infectious Diseases at the Academic Medical Center in Amsterdam, The Netherlands. He has published over 100 peer-reviewed manuscripts.

Dr. Kuijpers and his group have a broad interest in phagocyte function and development and in this respect neutropenia syndromes or phagocytic defects form an intrinsic part of their longstanding research lines and expertise.



Willem Kulik, Ph.D. — 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, Wageningen, The Netherlands.



Alanna Layton — Barth Syndrome Foundation, Inc.

Ms. Layton is the daughter of Michael and Shelley Bowen and sister of affected Barth individual, Michael Bowen, Jr. She earned a Master's degree in Mass Communication from the University of South Carolina in May of 2005 and wants to work in public relations. Miss Layton loves working with the Barth siblings and she helped coordinate the sibling sessions for the BSF 2006 Scientific/Medical and Family Conference.



Tal M. Lewin, Ph.D. — Research Assistant Professor, Department of Nutrition, School of Public Health and Medicine, University of North Carolina at Chapel Hill, Chapel Hill, SC

Dr. Lewin's research interests include the relationship between altered glycerolipid synthesis and heart dysfunction, acyltransferase structure and function, and Acyl-CoA synthetase structure and function.

Dr. Lewin holds a BSc in Biological Sciences from Carnegie Mellon University, Pittsburgh, and a PhD in Biochemistry from Duke University, Durham, North Carolina.



Melissa K. Maisenbacher, M.S., C.G.C. — Pediatric Genetic Counselor, Department of Pediatrics, Division of Genetics, University of Florida. Gainesville, FL

Ms. Maisenbacher's research/clinical interests include Dysmorphology, genetics of cardiomyopathies, and DiGeorge syndrome. She holds a BS in Biology from University of Notre Dame, Notre Dame, Indiana and an MSc in genetic counseling from Arcadia University, Philadelphia.



Shelia Mann — Family Services Chair, The Barth Syndrome Foundation, Inc.

Mrs. Mann has been a member of The Barth Syndrome Foundation, Inc. (BSF) since the beginning in 2002 and currently serves as the Family Services Chair for The Barth Syndrome Foundation. Shelia lives in Knoxville, Tennessee with her husband David, their 13 year old daughter English and their 9 year old son Benjamin who has Barth syndrome. Shelia also works part time as a Registered Dental Hygienist in Knoxville, Tennessee.



Katherine R. McCurdy — Vice President, Science and Medicine, Barth Syndrome Foundation, Inc.

Mrs. McCurdy is a founding member of the Barth Syndrome Foundation, Inc. (BSF) Board of Directors and serves as Vice President of Science and Medicine. With an MBA from the Harvard Business School, she has held various positions in the corporate world and also has served on several other nonprofit boards. Kate's most important credential, however, is that she is the mother of a wonderful 20-year old young man with Barth syndrome and his terrific 11-year old sister. She is completely committed to the goals of BSF.



Stephen B. McCurdy — Vice President and Chief Finance Officer, Finance and Development, Barth Syndrome Foundation, Inc.

Mr. McCurdy is the Dad of Will (20 years old) and Eliza (11 years old) and married to Kate McCurdy. He is a founding Board Member, Chairman and Chief Financial Officer of the Barth Syndrome Foundation, Inc. He is a graduate of the Harvard Business School and currently employed by American Express in New York City, The McCurdy's live in Larchmont, New York.



Lisa J. Merlo, Ph.D. — Post-Doctoral Fellow, Department of Psychiatry, University of Florida Department of Psychiatry, Gainesville, FL

Dr. Merlo's clinical interests primarily include working with children and adolescents who suffer from chronic psychiatric and medical conditions. She specializes in pediatric anxiety disorders and obsessive-compulsive disorder across the lifespan. Her research interests include psychosocial aspects of chronic conditions, including how a child's condition affects family, relationships, and overall quality of life. Dr. Merlo also conducts research examining the efficacy and effectiveness of cognitive-behavioral therapy and motivational interviewing interventions.



John A. Nackashi, M.D. — Division of General Pediatrics, University of Florida, Gainesville, FL; Professor and Chief of General Pediatrics, University of Florida, Gainesville, FL

Dr. Nackashi is a general pediatrician who has a special focus in providing coordinated and comprehensive services for children with special health care needs (CSHCN). He has served on regional and national committees advocating for CSHCN and serves as medical director of the Pediatric Care Coordination Program (PCCP), which provides primary care and coordinated care services for children with complex medical conditions.



Scott Oldewage — Parent of Affected Individual; Fundraising Committee, Barth Syndrome Foundation, Inc.

I am the father of a little "Superman". You all know him as Christian. My beautiful wife is Casie Oldewage and we have two other children. Our daughter Lexi just turned eight years old and Cooper is now 2. We have been members of the Barth Syndrome Foundation for the last 3 1/2 years. This organization has been a life-line and a life saver for our family over the years. I am also a member of the BSF Fundraising Committee.



Chrissie Petersen, B.S.W. — Family Support Coordinator, Sibshops Director, Achieve Tampa Bay

Ms. Petersen has held her current position for seven years. Achieve Tampa Bay, an affiliate of United Cerebral Palsy, has the mission to guide and assist families and individuals with any disability or barriers to achieve their full potential. She also works part time at the Children's Cancer Center as the Sibshop Coordinator for Sickle Cell Siblings and as the Teen Group Coordinator. (Sibshops is a program designed by Don Meyer for Siblings of children with disabilities/diseases.) Ms Petersen holds a degree in Social Work, 1998, from the University of South Florida and returned to study because of a promise made to a dying child. Chrissie did her internship at Achieve Tampa Bay.



Patrice X. Petit, Ph.D. — Director of Research CNRS (National Council for Scientific Research), Paris, France

Dr. Petit has held various positions at laboratories of CNRS, France from 1979 to the present.

Dr. Petit's interest is research into apoptosis (mechanisms inducing programmed cell death), as it pertains specifically to mitochondria, cancer and immunology. He has co-authored many scientific articles on this and associated subjects.

After graduating from the Lycee Henri IV with a Baccalaureat in Mathematics/Biology in 1971, he went on to attain his Ph.D. in Plant Physiology in 1979. He completed his State thesis in Plant Physiology in 1984.



Stephanie Rader, R.N. — Staff Nurse, Neonatal Intensive Care Unit, Cardinal Glennon Children's Medical Center, Saint Louis, MO

Ms. Rader is a neonatal intensive care nurse. In her role as a nurse she met a little patient who had special needs but he didn't have parents. She was inspired by this little boy to become a foster parent for children with special needs. Shortly after she received the approval to be a foster parent she received notice that a little girl needed a home. Stephanie took the child in and within weeks received another call about a baby with Barth syndrome who was in need of a home that could tend to his complex health needs. Without hesitation, Stephanie said these children are home and they are not going anywhere else when she learned they were both being placed for adoption. Stephanie is now the proud mommy of two four year olds separated by 11 weeks in age.



Peter Rehling, Ph.D. — Assistant Professor, Institute for Biochemistry and Molecular Biology, Albert Ludwig University of Freiburg, Freiburg, Germany

Dr. Rehling's research interests include protein transport across the mitochondrial inner membrane, biogenesis of protein complexes in the mitochondrial inner membrane and molecular bases of mitochondria associated diseases.



John G. Reiss, Ph.D. — Institute for Child Health Policy; Associate Professor, Department of Pediatrics, University of Florida, Gainesville, Florida

Dr. Reiss, who is a Counseling Psychologist by training, has focused over the last 15+ years on facilitating collaborative action among public and private sector organizations at the federal, regional and state levels; and between families and professionals to improve the organization, financing and delivery of health care for children and youth with special health care needs; and to promote full partnership with families. From 1993 – 2003 he directed a series of federally funded projects which provided training and technical assistance to States on improving systems of health care for children and youth.



Mindong Ren, Ph.D. — Assistant Professor, Department of Cell Biology, New York University School of Medicine, New York, NY

*Dr. Ren, a cell biologist by training, has long been interested in how various intracellular organelles are formed and how their derangement causes disease. His laboratory has been using the fruit fly *Drosophila* as a genetic model system to identify genes that function in the biogenesis of lysosome-related organelles such as melanosomes and platelet dense granules. Defective lysosome-related organelles underlie the pathology of a group of human genetic diseases such as Hermansky-Pudlak, Chediak-Higashi, and Griscelli syndromes. Supported by a Barth Syndrome Foundation research grant, his laboratory, in collaboration with Dr. Michael Schlame's group, has succeeded in generating the first animal model of Barth syndrome in *Drosophila*.*



Jonathan Rosenshine, M.A., M.Ed. — Buckley School, New York, NY; On-Site Director, Camp Viva, Pawling, NY; Educational Consultant, The Barth Syndrome Foundation, Inc.

Mr. Rosenshine has been an English teacher for 14 years in the New York metro area, and he is currently the Director of the Upper School at the Buckley School in New York City. He has worked as a camp counselor and director for many summers, and he has worked as an individual tutor for students in reading and writing skills. Jon has a BA in English and American Literature and an MA in Literature. He is working on a final paper towards his MEd degree from that program. In the 2004 BSF conference, Jon was a group leader for the boys, and he spoke to parents about the educational concerns facing their sons. In that year, he also wrote the BSF handbooks for how parents and educators can best advocate for students with Barth syndrome.



Michael Schlame, M.D. — Department of Anesthesiology, NYU School of Medicine and Cornell University, New York, NY; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc.

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.



Lynda M. Sedefian — Executive Administrative Assistant, Barth Syndrome Foundation, Inc.

Ms. Sedefian is the Executive Administrative Assistant for The Barth Syndrome Foundation, Inc. She also serves as the Secretary to the Board of Directors, as well as the Newsletter Editor. Lynda has been actively involved in the Foundation since its beginning. Ms. Sedefian is the mother of three children, two of whom have been affected by Barth syndrome. She resides in Altamont, New York with two surviving children Justin, 16 and Derek, 12 (affected individual). Prior to making the decision to leave full-time employment after the birth of her first son, Lynda was employed by the New York State Department of Health as a senior stenographer.



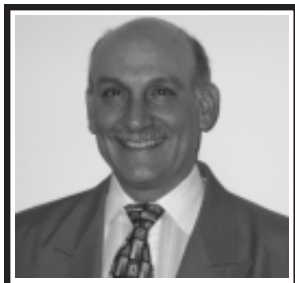
Robert E. Shaddy, M.D. — L. George Veasy Presidential Endowed Chair in Pediatric Cardiology; Professor of Pediatrics, Director of Pediatric Cardiology, University of Utah School of Medicine, Salt Lake City, UT; Medical Director, Heart Failure and Heart Transplantation Program, Primary Children's Medical Center, Salt Lake City, UT

Dr. Shaddy's research and clinical interests include pediatric heart failure and heart transplantation and immunology of valved allografts. He holds a B.A in Psychology, Summa Cum Laude, from Boston College, Massachusetts, 1976, M.D., Creighton University School of Medicine, Omaha, Nebraska, 1980. He completed a Pediatrics Internship and Residency at University of Iowa Hospitals and Clinics, Iowa City, Iowa, 1983. He was Fellow, Pediatric Cardiology, Cardiovascular Research Institute, University of California, San Francisco, 1983 to 1986.



Elizabeth Shenkman, Ph.D. — Professor of Epidemiology and Health Policy Research and Pediatrics, Chair, Department of Epidemiology and Health Policy Research Director, Institute for Child Health Policy, College of Medicine, University of Florida, Gainesville, FL

Dr. Shenkman's areas of specialization include assessing the relationship between health plan organizational characteristics, provider practice setting characteristics, and provider reimbursement on the quality and outcomes of care for children and adults, including those with chronic conditions. Dr. Shenkman is a nationally recognized expert related to examining children's quality of care, particularly for public insurance programs such as Medicaid and the State Children's Health Insurance Program. She is the Principal Investigator on five state projects of Florida's Medicaid reform pilot project.



Ariel A. Sherbany, M.D., Ph.D. — Pediatric Neurologist, Pediatric Neurology of Hudson Valley, Nanuet, NY; Clinical Assistant Professor of Neurology and Pediatrics, New York Medical College, Valhalla, NY; Assistant Clinical Professor of Neurology, Columbia University, New York, NY

Dr. Sherbany is a pediatric neurologist in private practice in Rockland County, New York. He is affiliated with New York Medical College and Columbia University. His clinical interests include epilepsy, neonatal neurology and neurometabolic disease.



Carolyn T. Spencer, M.D. — Assistant Professor, Director, Pediatric Echocardiography Laboratory, Division of Pediatric Cardiology, University of Florida College of Medicine, Gainesville, FL; Principal Investigator, Barth Syndrome Medical Database & Biorepository

Dr. Spencer is a graduate of University of North Carolina and completed her residency and Chief Residency in Pediatrics at the University of Florida. She continued her fellowship in Pediatric Cardiology at the University of Florida, and completed her sub-specialty training in pediatric echocardiography at Children's Hospital Boston. She is currently an Assistant Professor of Pediatric Cardiology and Director of Pediatric Echocardiography Laboratory at UF. She has a long-standing interest in Barth syndrome and this is the 3rd BSF Family and Scientific Conference in which she has participated. She is a recipient of a Barth Syndrome Foundation Grant Award to study the cardiac and clinical phenotype in Barth syndrome, as well as the Principal Investigator of the new Barth Syndrome Medical Database & Biorepository.



Colin G. Steward, M.A., B.M., B.Ch., F.R.C.P., F.R.C.P.C.H., Ph.D. — Bristol Royal Hospital for Children, Bristol, UK; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc.

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. He first became interested in Barth syndrome after realizing that his department had missed the correct diagnosis in several children with neutropenia. He has since diagnosed 10 further families presenting with the disease in South West England and Wales, and organizes annual clinics for these families. Dr. Steward believes that Barth syndrome is seriously under-diagnosed because it presents in many different ways, and is trying to raise awareness of the disease.



Eric A. Storch, Ph.D. — Assistant Professor of Pediatrics and Psychiatry, University of Florida, Gainesville, FL

Dr. Storch's ongoing research includes examining the efficacy of telehealth in the delivery of psychological service in difficult to manage youth with Type 1 Diabetes, D-Cycloserine augmentation of cognitive-behavioral therapy for obsessive-compulsive disorder and the study of psychosocial factors associated with Barth syndrome.



Jill Storch, M.Ed. — University of Florida, Gainesville, FL

Mrs. Storch received her Master's Degree in Special Education with a focus on severe and multiple disabilities and inclusion from the University of Florida. She is currently a doctoral candidate at the University of Florida. She has taught in inclusive settings and was most recently an Inclusion Specialist for Alachua County Public Schools in Gainesville, Florida. Her interests lie in parent advocacy, teacher training and systemic change related to inclusive practices for students and adults with disabilities.



Arnold W. Strauss, M.D. — James C. Overall Professor and Chair, Department of Pediatrics, Professor of Molecular Physiology and Biophysics; Director, Vanderbilt Children's Hospital, Nashville, TN

Dr. Strauss' research interests include the molecular basis of disorders of nuclear genes coding for enzymes of the mitochondrial fatty acid oxidation pathway. This pathway breaks down fat to generate energy. Patients with mutations in these genes suffer cardiomyopathy (heart muscle dysfunction), liver failure (a Reye's-syndrome like picture), and sudden infant death. His research also involves understanding the genetic causes of congenital heart disease in children. His research was recognized by the Mead Johnson Award for Excellence in Pediatric Research. He has published more than 200 research articles.



Lauren A. Stutts, B.S. — Department of Clinical and Health Psychology, University of Florida, Gainesville, FL

Ms. Stutts received a B.S. in Psychology with a concentration in Medical Humanities from Davidson College in 2005. She has conducted grant-funded research investigating the effect of chronic illness and psychogenic bodily reactions in pediatric and adult populations, taught a course in psychological research methods, and served as an officer in a professional society. Laren joined the Cardiac Psychology Research Team in the fall of 2005. She is the principal investigator of a study investigating the psychological aspects of cardiac device recall in implantable cardioverter defibrillator patients. Additional research interests in the field include positive psychology, medical ethics, and general issues in the biopsychosocial care of patient health.



Eric Testet, Ph.D. — Assistant-Professor, Biochemical Engineering, Membrane Biogenesis Laboratory, University of Bordeaux 2: Victor Segalen, Bordeaux, France

Dr. Testet's research interests include characterization of a glycerolipid acyltransferase family in yeast. Dr. Testet holds a PhD from the Institut National Polytechnique de Toulouse, 1987.



Jeffrey A. Towbin, M.D. — Chief, Pediatric Cardiology, Texas Children's Hospital; Professor, Departments of Pediatrics, Molecular & Human Genetics, Cardiovascular Sciences, Baylor College of Medicine; Director, Phoebe Willingham Muzzy Pediatric Molecular Cardiology Laboratory; Texas Children's Hospital Foundation Chair in Pediatric Cardiac Research, Houston, TX; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc.

Dr. Towbin is a pediatric cardiologist whose major interests include cardiomyopathy, cardiovascular genetics and cardiac transplantation. In addition to his clinical practice, he also conducts research in related areas, and has written numerous articles.



Jeanette Van Duyne, P.T. — Program Manager, Parris Pediatric Rehabilitation, Titusville, FL

Ms. Van Duyne is a physical therapist and program manager for Parrish Pediatric Rehabilitation in Titusville, FL. She graduated from Utica College of Syracuse University in 1999 with a Bachelors of Science in Physical Therapy. She has worked with the pediatric population for 5 years in various settings. Jeanette has taken a variety of continuing education courses, including a dynamic bracing workshop, a Theratogs course, pediatric aquatics, partial weight-bearing gait training, the TOPSEI program, NDT treatment of the baby, and functional strengthening in the neurologically impaired child.



Ronald J. A. Wanders, Ph.D. — Professor of Enzymology and Inherited Metabolic Diseases, University of Amsterdam, Amsterdam, The Netherlands; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc.

Professor 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.



Susan V. Wilkins, R.N. — Board Member, Barth Syndrome Foundation, Inc.

Mrs. Wilkins is a founding member of The Barth Syndrome Foundation, Inc. (BSF) and has served on the Board of Directors since its inception. Sue lives in Lincoln, NE with her husband Mike, their son John (24 years old) who has Barth syndrome and their three dogs. Sue's daughter Jess and her new husband Mark are living in Lincoln as well, for the moment, before they both head off to graduate school. Sue is a Registered Nurse who works part time at Lincoln's Community Blood Bank, which she enjoys very much.

FRIENDS OF BSF

• On behalf of the Barth Syndrome Foundation, we
• acknowledge and thank all volunteers who have
• worked together to make this conference a success!

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• We would like to thank all those involved in the two
• days of clinics and consults. Their support will allow
• BSF to collect the crucial data needed to support the
• Barth Syndrome Medical Database and Biorepository.

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in the lives of these boys and young men.*



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Cracking the Mysteries of Barth Syndrome

**A Multi-disciplinary Meeting of Principal Physicians and
Scientists Working Internationally on Major Biochemical
and Clinical Questions to be Answered about Barth
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