

Barth Syndrome  
International  
Scientific/Medical and  
Family Conference

Disney's Coronado Springs Resort  
Lake Buena Vista, Florida

July 8-12, 2004



Barth Syndrome  
Foundation

[www.barthsyndrome.org](http://www.barthsyndrome.org)

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

**The Barth Syndrome  
Foundation's  
"2004 International  
Scientific/Medical  
and Family Conference"  
is being  
Co-Sponsored by**

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Dear Friends,

It is an immense honor to welcome you to The Barth Syndrome Foundation's (BSF) "2004 International Scientific/Medical and Family Conference" at Disney's Coronado Springs Resort. We are delighted to announce this as being a record-breaking year for attendance. This is in no small part due to the impressive agenda comprised of experts from around the globe representing a variety of subspecialties and scientific expertise with regard to Barth syndrome.

This conference is unlike any other conference, in that it combines presentations of bench and clinical science, encourage future collaborative efforts among scientists and families. This year we have also included an additional tract of youth sessions for affected children and siblings. We hope everyone will take advantage of BSF's efforts to help all who are affected by this disorder. We also hope to see you at our social events we have planned.

We are all eager to hear of the scientific advances made through the grants which BSF has awarded over the previous two years. It is our desire for this seed money to glean insight into a better understanding about this complex disorder which is still claiming the lives of affected individuals. I am certain when you hear the presentations provided you will recognize how fortunate we have been to have such high caliber scientists committed to our cause.

This year's conference will be recorded on DVD's and made available to physicians and families around the world who otherwise would not be able to learn what you are learning by attending this conference. It is our desire to help all families and physicians, regardless of region, who are caring for those with Barth syndrome. We are also in hopes that these DVD's will shed light on a little known disorder called Barth syndrome, encouraging other individuals to be diagnosed in a timely manner.

We are keenly aware of the faces that will never be with us again after losing their battle to Barth syndrome. The faces of the children whom we all came to know well are forever etched in our memories. They may be gone but with BSF they are never forgotten.

I would like to acknowledge our dedicated conference committee Rosemary Baffa, Shelley Bowen, Anna Dunn, Lynn Elwood, Julie Fairchild, Christiane Hope, Jan Kugelmann, Alanna Layton, Shelia Mann, Katherine McCurdy, MaryLou Pagano, and Lynda Sedefian. They have been working on making this the best conference yet, working diligently over the past twelve months obtaining donations, sending out invitations, and working on the details that many may not even notice, but nonetheless important details. On behalf of BSF, I would also like to thank all those physicians and educators who have graciously volunteered their time to our families by participating in the clinics which will be held on Thursday, July 8th and Friday, July 9th, 2004.

Finally, I would like to recognize the many contributors, great and small, who believed in the importance of this conference and came to our aid financially to assist us in defraying expenses. Your contributions are greatly appreciated and well invested.

Respectfully

*Shelley Bowen*

Valerie ("Shelley") M. Bowen  
President  
The Barth Syndrome Foundation, Inc.

# **AGENDA FOR JULY 2004 BARTH SYNDROME SCIENTIFIC AND MEDICAL MEETING**

## **FRIDAY, JULY 9, 2004**

19:00 – 21:00 Registration and Reception (**Durango 1 & 2**)

## **SATURDAY, JULY 10, 2004**

8:15 – 8:45 MORNING COFFEE AND DANISH AVAILABLE (**Coronado M – T Lobby**)

### **Introduction and Overview (Monterrey 1)**

8:45 – 8:55 “Welcome and Opening Remarks”

~ *Katherine R. McCurdy – V.P. Science and Medicine, Barth Syndrome Foundation, Inc.*

8:55 – 9:10 “Perspective on this Meeting”

~ *John Fakunding, Ph.D. — National Heart, Lung and Blood Institute, NIH, Bethesda, MD*

9:10 – 9:25 “Overview of What is New with Barth Syndrome”

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

### **Diversity and Expression of G4.5 Gene Products (Monterrey 1)**

9:25 – 9:30 Barth Family Personal Introduction

~ *Shelia Mann – Barth Syndrome Foundation, Inc.*

9:30 – 10:00 “TAZ mRNAs in Barth Syndrome Individuals”

~ *Iris L. Gonzalez, Ph.D. – A. I. DuPont Children’s Hospital, Wilmington, DE*

10:00 – 10:30 “Function of the TAZ-gene and Characterization of its Gene Products”

~ *Frederic Vaz, Ph.D. – Academic Medical Center, Amsterdam, The Netherlands*

10:30 – 10:45 BREAK (**Coronado M – T Lobby**)

10:45 – 11:15 “TAZ1 Gene Function in Yeast: a Molecular Model for Barth Syndrome”

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

### **Cardiolipin Metabolism (Monterrey 1)**

11:15 – 11:20 Barth Family Personal Introduction

~ *Lynn Elwood – Barth Syndrome Foundation, Canada*

11:20 – 11:50 “Effect of Murine TAZ Overexpression on Phospholipid Metabolism”

~ *Grant M. Hatch, Ph.D. – University of Manitoba, Winnipeg, Manitoba, Canada*

11:50– 12:20 “Tafazzin Function and Mitochondrial Pathology in Barth Syndrome”

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

12:20 – 13:30 LUNCH (**Coronado B - D**)

### **Barth Syndrome Disease Models and Future Research (Monterrey 1)**

13:30 – 13:35 Barth Family Personal Introduction

~ *Michael Wilkins, M.D. – Barth Syndrome Foundation, Inc.*

13:35 – 14:00 “Bid and Cardiolipin Metabolism: Impact on Neutropenia and Lymphoma Predisposition”

~ *Mauro Degli Esposti, Ph.D. – University of Manchester, Manchester, UK*

- 14:00 – 14:25 “Induction of Apoptosis in Cardiomyocytes by Alteration of the Acylation State of Mitochondrial Phospholipids”  
~ *William Dowhan, Ph.D. – University of Texas, Houston, TX*
- 14:25 – 14:45 BREAK (**Coronado M – T Lobby**)
- 14:45 – 15:10 “Spectrum of Acyltransferase Biochemistry”  
~ *Rosalind A. Coleman, M.D. – UNC-Chapel Hill, Chapel Hill, NC*
- 15:10 – 15:35 “Genetics, Genomics and Proteomics”  
~ *Susan Old, Ph.D. – National Heart, Lung and Blood Institute, NIH, Bethesda, MD*
- 15:35 – 16:00 “Barth Animal Models”  
~ *Arnold W. Strauss, M.D. – Vanderbilt University, Nashville, TN*
- 16:00 – 17:00 Brainstorming Session Regarding Future Directions of Barth Scientific Research  
~ *Richard I. Kelley, M.D., Ph.D., moderator – Kennedy Krieger Institute, affiliate of Johns Hopkins Medical Institutions, Baltimore, MD*
- 17:00 – 17:30 **FREE TIME FOR THOSE ON BSF’S SCIENTIFIC AND MEDICAL ADVISORY BOARD**
- 17:30 – 19:30 **MEETING OF BSF’S SCIENTIFIC AND MEDICAL ADVISORY BOARD**
- 17:00 – 19:00 FREE TIME for those who do not serve on BSF’s Scientific and Medical Advisory Board
- 19:00 – 22:00 SOCIAL EVENT (with Barth Families) FOR ALL (**Coronado H**)

**SUNDAY, JULY 11, 2004**

- 8:45 – 9:15 MORNING COFFEE AND DANISH AVAILABLE (**Coronado M – T Lobby**)

**Natural History of Pathology and Functional Abnormalities in the Barth Heart (Monterrey 1)**

- 9:15 – 9:20 Barth Family Personal Introduction  
~ *Rosemary Baffa – Barth Syndrome Foundation, Inc.*
- 9:20 – 9:55 “Barth Cardiomyopathy”  
~ *Carolyn T. Spencer, M.D. – University of Florida, Gainesville, FL*
- 9:55 – 10:30 “Cardiac Arrhythmia in Barth Syndrome”  
~ *Randall Bryant, M.D. – University of Florida, Gainesville, FL*
- 10:30 – 11:00 BREAK (**Coronado M – T Lobby**)

**Other Clinical Aspects of Barth Syndrome (Monterrey 1)**

- 11:00 – 11:05 Barth Family Personal Introduction  
~ *Jeanette Thorpe – Barth Syndrome Foundation, Inc.*
- 11:05 – 11:40 “Neutropenia In Barth Syndrome”  
~ *Colin G. Steward, B.M., B.Ch., M.R.C.P., F.R.C.Pc.H., Ph.D. – Bristol Royal Hospital for Sick Children, Bristol, UK*
- 11:40 – 12:15 “Neurologic Manifestations of Barth Syndrome”  
~ *Tyler Reimschisel, M.D. – Kennedy Krieger Institute, affiliate of Johns Hopkins Medical Institutions, Baltimore, MD*

12:15 – 13:30 LUNCH WITH BARTH FAMILIES (GROUP PHOTO TAKEN) (**Coronado L**)

13:30 – 14:00 “PT/OT, Orthotics and Sensitivities in Barth Children”  
~ *Raghad Schroeder, O.T.R./L. – Theraplay, Clifton Park, NY*

14:00 – 14:30 “The Underdiagnosis of Barth Syndrome”  
~ *Karla Bowles, Ph.D. – Baylor College of Medicine, Houston, TX*

14:30 – 15:00 BREAK (**Coronado M – T Lobby**)

### **Barth Syndrome Foundation, Inc.**

15:00 – 15:05 Barth Family Personal Introduction  
~ *Stephen Kugelmann – Barth Syndrome Foundation, Inc.*

15:05 – 15:25 “BSF Registry and Clinical Database”  
~ *Gerald F. Cox, M.D., Ph.D. – Genzyme Corporation, Cambridge, MA*

15:25 – 16:00 “Discussion of Barth Clinic Model”  
~ *Richard I. Kelley, M.D., Ph.D. – Kennedy Krieger Institute, affiliate of Johns Hopkins Medical Institutions, Baltimore, MD*  
~ *Colin G. Steward, B.M., B.Ch., M.R.C.P., F.R.C.Pc.H., Ph.D. – Bristol Royal Hospital for Sick Children, Bristol, UK*

16:00 – 16:20 “Barth Syndrome Foundation Update”  
~ *Valerie “Shelley” M. Bowen – President, Barth Syndrome Foundation, Inc.*

### **Closing**

16:20 – 16:40 “Closing Remarks and Perspective”  
~ *Peter G. Barth, M.D., Ph.D. – Emma Children’s Hospital / AMC, Amsterdam, The Netherlands*

## **MONDAY, JULY 12, 2004**

8:30 – 9:00 MORNING COFFEE AND DANISH AVAILABLE (available all morning) (**Coronado A – G Lobby**)

9:00 – 11:00 Working Meetings to Finalize Drafts of Barth Syndrome Treatment Guidelines for Various Aspects of the Disorder

- Cardiology (*Barry J. Byrne, M.D., Ph.D., leader*) (**Coronado B**)
- Hematology (*Colin G. Steward, B.M., B.Ch., M.R.C.P., F.R.C.Pc.H., Ph.D., leader*) (**Coronado C**)
- Neurology (*Peter G. Barth, M.D., Ph.D., leader*) (**Coronado D**)
- General Pediatrics, Diagnostics, Metabolics, Anesthesiology, Other (*Richard I. Kelley, M.D., Ph.D., leader*) (**Coronado E**)

11:00 – 12:00 Discussion of Clinical Ideas and Looking at the WHOLE Barth Patient  
~ *Richard I. Kelley, M.D., Ph.D., moderator – Kennedy Krieger Institute, affiliate of Johns Hopkins Medical Institutions, Baltimore, MD* (**Coronado B - E**)

12:00 – 12:45 LUNCH (**Fiesta Ballroom**)

**Durango 1 & 2**

12:45 – 15:30 All are Invited to Join the Family Meeting for:

12:45 – 14:15 Parent PANEL on How to Care For, Cope With, and Advocate For Your Barth Child

14:15 – 15:00 What We Have Learned From Our Children  
~ *Reports From Group Leaders of Barth Boys' and Siblings' Groups*

15:00 – 15:30 Closing Remarks  
~ *Valerie "Shelley" M. Bowen – President, Barth Syndrome Foundation, Inc.*

15:30 – 19:00 FREE TIME

19:00 – 22:00 GATHERING by "The Dig" For All (**Coronado pool**)



# **AGENDA FOR JULY 2004 BARTH SYNDROME FAMILY MEETING**

## **FRIDAY, JULY 9, 2004**

19:00 – 21:00 Registration and reception (**Durango 1 & 2**)

## **SATURDAY, JULY 10, 2004**

8:30 – 9:00 MORNING COFFEE AND DANISH AVAILABLE (**Coronado M – T Lobby**)

### **Introduction and Overview (Durango 1 & 2)**

9:00 – 9:15 “Welcome and Opening Remarks”

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

9:15 – 9:45 “What We Now Know About Barth Syndrome”

~ Peter G. Barth, M.D., Ph.D. – Emma Children’s Hospital / AMC, Amsterdam, The Netherlands

### **PANEL on Neurologic Aspects of Barth Syndrome (Durango 1 & 2)**

9:45 – 10:00 “Neurologic Manifestations of Barth Syndrome”

~ Tyler Reimschisel, M.D. – Kennedy Krieger Institute, affiliate of Johns Hopkins Medical Institutions, Baltimore, MD

10:00 – 10:20 “Benefits of PT/OT Interventions and Orthotics for a Barth Boy”

~ Paula Geigle, P.T., Ph.D., NCCAM Postdoctoral Fellow - University of Pennsylvania Medical School, Philadelphia, PA

~ Raghad Schroeder, O.T.R./L. – Theraplay, Clifton Park, NY

10:20 – 10:30 Question and Answer Session (Tyler Reimschisel, M.D., moderator)

10:30 – 10:45 BREAK (**Coronado M – T Lobby**)

### **PANEL on the Cardiac Aspects of Barth Syndrome (Durango 1 & 2)**

10:45 – 11:00 “Cardiomyopathy”

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

11:00 – 11:15 “Arrhythmias”

~ Randall Bryant, M.D. – University of Florida, Gainesville, FL

11:15 – 12:30 Question and Answer Session (Frederick J. Fricker, M.D. – University of Florida, Gainesville, moderator)

12:30 – 13:30 LUNCH (**Coronado B - D**)

### **Family Issues with Child with Chronic Illness (Durango 1 & 2)**

13:30 – 14:45 “Siblings of People with Barth Syndrome: Unique Concerns, Unique Opportunities”

~ Donald J. Meyer – Sibling Support Project of the Arc of the United States, Seattle, WA

14:45 – 15:00 BREAK (**Coronado M – T Lobby**)

### **PANEL on the Neutropenia Aspects of Barth Syndrome (Durango 1 & 2)**

15:00 – 15:15 “Neutropenia in Barth Syndrome”

~ Colin G. Steward, B.M., B.Ch., M.R.C.P., F.R.C.Pc.H., Ph.D. – Bristol Royal Hospital for Sick Children, Bristol, UK

15:15 – 15:30 “Barth Syndrome and the Severe Chronic Neutropenia International Registry”  
~ David C. Dale, M.D. – University of Washington, Seattle, WA

15:30 – 16:00 Questions and Answer Session (David C. Dale, M.D., moderator)

16:00 – 19:00 FREE TIME

19:00 – 22:00 SOCIAL EVENT (with scientists and physicians) FOR ALL (**Coronado H**)

### **SUNDAY, JULY 11, 2004**

8:30 – 9:00 MORNING COFFEE AND DANISH AVAILABLE (**Coronado M – T Lobby**)

#### **Barth Syndrome Scientific Research (Durango 1 & 2)**

9:00 – 9:45 PANEL on Updates on Barth Syndrome Research

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

~ Iris L. Gonzalez, Ph.D. – A. I. DuPont Children’s Hospital, Wilmington, DE

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

~ Grant M. Hatch, Ph.D. – University of Manitoba, Winnipeg, Manitoba, Canada

~ Frederic Vaz, Ph.D. – Academic Medical Center, Amsterdam, The Netherlands

~ Yang Xu, M.D., Ph.D. – New York University School of Medicine, New York, NY

~ Arnold W. Strauss, M.D. – Vanderbilt University, Nashville, TN

~ (Michael Schlame, M.D. – New York University Hospital, New York, NY will also be available to answer questions)

9:45 – 10:00 Question and Answer Session (Richard I. Kelley, M.D., Ph.D., moderator)

10:00 – 10:20 PANEL on What You Can Do To Advance Barth Research

BSF Registry: Gerald F. Cox, M.D., Ph.D. – Genzyme Corporation, Cambridge, MA

BSF Blood and Tissue Bank: Susan V. Wilkins, R.N. and Michael D. Wilkins, M.D. – Barth Syndrome Foundation, Inc.

10:20 – 10:30 Question and Answer Session (Gerald F. Cox, M.D., Ph.D., moderator)

10:30 – 10:45 BREAK (**Coronado M – T Lobby**)

#### **Practical Advice for Routine Medical Care of Those with Barth Syndrome (Durango 1 & 2)**

10:45 – 11:45 PANEL with Brief Introductions, Followed by Question and Answer Session

~ Katherine R. McCurdy, moderator – V.P. Science and Medicine, Barth Syndrome Foundation, Inc.

~ Patricia Blanco, M.D. – University Pediatrics, Sarasota, FL

~ Mary Ann Bonilla, M.D. – St Joseph’s Children’s Hospital, Paterson, NJ

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

~ Annette Feigenbaum, M.D., Ch.B., F.R.C.P.C. – Hospital for Sick Children, Toronto, Ontario, Canada

~ Rebecca Kern, M.G.C. – Kennedy Krieger Institute, Baltimore, MD

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

11:45 – 12:05 “The Transition from Child-Centered to Adult-Oriented Medical Care”

~ John G. Reiss, Ph.D. – University of Florida, Gainesville, FL

12:05 – 12:15 Question and Answer Session (John G. Reiss, Ph.D., moderator)

12:15 – 13:30 LUNCH WITH PHYSICIANS AND SCIENTISTS (GROUP PHOTO TAKEN) (**Coronado L**)

**Barth Metabolism and Nutrition (Durango 1 & 2)**

13:30 – 13:45 “Barth Syndrome Metabolics and Nutrition”

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

13:45 – 14:00 Question and Answer Session (*Richard I. Kelley, M.D., Ph.D., moderator*)

**PANEL on Education (Durango 1 & 2)**

14:00 – 14:15 “Draft of Barth Educational Handbooks for Teachers/Administrators, Parents and Barth Students”

~ *Jonathan Rosenshine, M.A., M.Ed. – Buckley School, New York, NY*

14:15 – 15:15 Brief Introductions of Additional People Below, Followed by Question and Answer Session for All

~ *Valerie “Shelley” M. Bowen, moderator – President, Barth Syndrome Foundation, Inc.*

~ *Joan C. Stoner, Ed.D. – Capella University (internet based), offices in Minneapolis, MN*

~ *Eileen Q. Juico, M.A., M.Ed. – Rye Country Day School, Rye, NY*

15:15 – 15:30 BREAK (Coronado M – T Lobby)

**PANEL on Psychosocial Aspects of Barth Syndrome (Durango 1 & 2)**

15:30 – 16:30 Open Forum for Discussion

~ *Jules Spotts, Ph.D., moderator – Child Guidance Center, New Canaan, CT*

~ *Jaclyn M. Butera, M.S.W., C.S.W., M.Ed. – Rye Country Day School, Rye, NY*

~ *Adrienne Kovacs, Ph.D., – University of Florida, Gainesville, FL*

**MONDAY, JULY 12, 2004**

8:00 – 8:30 MORNING COFFEE AND DANISH AVAILABLE (available all morning) (Coronado A – G Lobby)

**BSF – Where Do We Go From Here? (Durango 1 & 2)**

8:30 – 9:00 Overview of BSF

~ *Valerie “Shelley” M. Bowen – President, Barth Syndrome Foundation, Inc.*

9:00 – 11:45 Small Groups Rotating through Discussions on Various Topics by BSF Members  
(with 30 minute Coffee Break half-way through)

- Awareness and Outreach (*Stephen Kugelmann, Lynn Elwood; moderators*) (Yucatan 1)
- Family Support (*Anna Dunn, Christiane Hope, Shelia Mann, Sharon Olson; moderators*) (Yucatan 2)
- Science and Medicine (*Katherine R. McCurdy, Catharine L. Ritter, Carolyn Gravitt; moderators*) (Yucatan 3)
- Fundraising (*Jan Kugelmann, Thomas Monahan, Stephen B. McCurdy; moderators*) (Coronado G)

11:45 – 12:45 LUNCH (Fiesta Ballroom)

**Parent PANEL on How to Care For, Cope With, and Advocate For Your Barth Child (Durango 1 & 2)**

12:45 – 14:15 Brief Introductions, Followed by Discussion

~ *Susan V. Wilkins, moderator – US, 22 Year Old Son*

~ *Michaela Damin – UK, 5 Year Old Son*

~ *Stephen B. McCurdy – US, 18 Year Old Son*

~ *Catharine L. Ritter – Canada, 13 Year Old Son*

~ *Lynda Sedefian – US, 11 Year Old Son*

**What We Have Learned From Our Children (Durango 1 & 2)**

14:15 – 15:00 Reports from Group Leaders of Barth Boys' and Siblings' Groups

- ~ *B.J. Develle, Barth Boys Aged 8-11 Years*
- ~ *Jon Rosenshine, Barth Boys Aged 12-15 Years*
- ~ *Jacquie Butera, Barth Boys Aged 16 Years +*
- ~ *Greta Develle, Siblings Aged 8-11 Years*
- ~ *Erica Frisby-Moore, Siblings Aged 12-15 Years*
- ~ *Alanna Layton, Siblings Aged 16 Years and Older*

**Closing (Durango 1 & 2)**

15:00 – 15:30 Closing Remarks

- ~ *Valerie "Shelley" M. Bowen – President, Barth Syndrome Foundation, Inc.*

15:30 – 19:00 FREE TIME

19:00 – 22:00 GATHERING by "The Dig" For All (Coronado pool)

## **AGENDA FOR BARTH SYNDROME BOYS AGES 8 - 11**

### **FRIDAY, JULY 9, 2004**

19:00 - 21:00 **Friday Night at the Movies (Acapulco)**

### **SATURDAY, JULY 10, 2004**

8:30 – 9:00 **CONTINENTAL BREAKFAST (Coronado M – T Lobby)**

9:00 – 9:15 **Welcome by Group Leader (Suite 1)**  
~ B.J. Develle

9:15 – 9:45 **What is Barth Syndrome? (Suite 1)**  
*This is a session with learning aids about how the heart and blood cells that fight infection work. We will also talk about how our bodies grow and look at that funny chart that the doctor works on every time we go to see him.*  
~ Shelley Bowen, President, Barth Syndrome Foundation, Inc.

9:45 – 10:30 **How Do I Speak up for Myself? (Issues surrounding illness, school and social activities) (Suite 1)**  
*A child with Barth syndrome needs to learn early on when to tell the teacher when he is not feeling well or if he needs to call home. He needs to be receptive to the subtle changes in his body to alert his parents that things just aren't right.*  
~ B.J. Develle

10:30 – 10:45 **BREAK (Coronado M – T Lobby)**

10:45 – 11:15 **Genetics (Suite 1)**  
*Genetics will be explained in terms specific to the age group. Genetic counselor Becky Kern will be teaching genetics with a really fun hands-on approach.*  
~ Becky Kern, M.S., C.G.C.

11:15 – 12:00 **Photographs (Coronado M)**

12:00 – 12:30 **Group Activity (Cancun)**  
~ B.J. Develle

12:30 – 13:30 **LUNCH (Coronado E- G)**

13:30 – 16:00 **Childcare (Cancun)**  
~B.J. Develle

### **SUNDAY, JULY 11, 2004**

8:30 – 9:00 **BREAKFAST (Coronado M – T Lobby)**

9:00 – 12:15 **Childcare (Cancun)**  
Group Project (Banner)  
~ B.J. Develle

12:15 – 13:30 **LUNCH (Coronado L)**

13:30 – 14:45 **Childcare (Cancun)**

14:45 – 15:00 **BREAK (Coronado M – T Lobby)**

15:00 – 16:00 **Childcare (Cancun)**  
Group Project (Puzzle)  
~B.J. Develle

**MONDAY, JULY 12, 2004**

- 8:30 – 9:00 **CONTINENTAL BREAKFAST** (Coronado A – G Lobby)
- 9:00 – 10:30 **What Do I Have to Say? What Do I Have to Offer?** (Coronado M)  
~ B.J. Develle
- 10:30 - 10:45 **BREAK**
- 10:45 - 11:45 **Childcare** (Cancun)
- 11:45 – 12:45 **LUNCH** (Fiesta Ballroom)
- 12:45 – 14:15 **Childcare** (Cancun)
- 14:15 – 15:00 **Report to Group** (Meeting with parents) (Durango 1 & 2)  
~ B.J. Develle

**AGENDA FOR BARTH SYNDROME SIBLINGS AGES 8 – 11**

**FRIDAY, JULY 9, 2004**

- 19:00 - 21:00 **Friday Night at the Movies** (Acapulco)

**SATURDAY, JULY 10, 2004**

- 8:30 – 9:00 **CONTINENTAL BREAKFAST** (Coronado M – T Lobby)
- 9:00 – 9:15 **Welcome and Opening Remarks** (El Paso 2)  
~ Greta Develle
- 9:15 – 10:30 **Sibling Support Project** (El Paso 2)  
*Eight to 11 year old sibs of boys with Barth syndrome will join Don Meyer to meet other sibs, have some fun, play some great games and talk about the good - and not-so-good parts of having a brother with Barth syndrome with others who get it! Don is the Director of the Sibling Support Project and author and editor of many books on sibling issues.*  
~ Don Meyer, Director
- 10:30 – 10:45 **BREAK** (Coronado M – T Lobby)
- 10:45 – 11:15 **Genetics** (Suite 1)  
*Genetics will be explained in terms specific to the age group. Genetic counselor Becky Kern will be teaching genetics with really fun hands-on approach.*  
~ Becky Kern, M.S., C.G.C.
- 11:15 – 12:30 **Group Activity** (Cancun)  
~ Greta Develle
- 12:30 – 13:30 **LUNCH** (Coronado E - G)
- 13:30 – 16:00 **Childcare** (Cancun)

**SUNDAY, JULY 11, 2004**

- 8:30 – 9:00 **CONTINENTAL BREAKFAST** (*Coronado M – T Lobby*)
- 9:00 – 12:15 **Group Activity (Puzzle)** (*Cancun*)  
(Childcare)  
~ Greta Develle
- 12:15 – 13:30 **LUNCH** (*Coronado L*)
- 13:30 – 14:45 **Childcare** (*Cancun*)  
~ Greta Develle
- 14:45 – 15:00 **BREAK** (*Coronado M - T*)
- 15:00 – 16:00 **Childcare** (*Cancun*)  
~ Greta Develle

**MONDAY, JULY 12, 2004**

- 8:30 – 9:00 **CONTINENTAL BREAKFAST** (*Coronado A - G Lobby*)
- 9:00 – 10:00 **What Do I Have to Say? What Do I Have to Offer?** (*Coronado M*)  
~ Greta Develle
- 10:00 – 11:45 **Childcare** (*Cancun*)
- 11:45 – 12:45 **LUNCH** (*Fiesta Ballroom*)
- 12:45 – 14:15 **Childcare** (*Cancun*)
- 14:15 – 15:00 **Report to Group** (Meeting with parents) (*Durango 1 & 2*)  
~ Greta Develle

**AGENDA FOR BARTH SYNDROME BOYS AGES 12 – 15**

**FRIDAY, JULY 9, 2004**

- 19:00 - 21:00 **Friday Night at the Movies** (*Acapulco*)

**SATURDAY, JULY 10, 2004**

- 8:00 – 9:00 **Photographs** (*Coronado M*)
- 8:30 – 9:00 **BREAKFAST** (*Coronado M – T Lobby*)
- 9:00 – 9:15 **Welcome and Opening Remarks** (*Coronado Q*)  
*Aims of the weekend will be explained to the group as well as introductions of the group's participants*  
~ Jon Rosenshine, M.A., M.Ed.
- 9:15 – 9:45 **What Are You Doing to Me Echo** (*Coronado Q*)  
*“What are they looking at when they do an echo on me? What are all of those lines and colors? What is the difference between an ejection fraction and a shortening fraction? How do you figure that out and what do they mean?” These are just some of the important topics that will be addressed during this session. The mystery of the echocardiogram will be unveiled.*  
~ Barry Byrne, M.D., Ph.D.  
~ Dan Peterson, Echo Stenographer

- 9:45 – 10:00 **What Are You Doing to Me EKG (Coronado Q)**  
*Do you ever wonder what those peaks are on that shiny orange grid? During this session boys will learn what the different lines mean. “What is a P, Q, R, S, T other than letters of the alphabet and what do they mean?” How can you tell when mine looks different?” These will be some of the important topics addressed during this session.*  
 ~ Barry Byrne, M.D., Ph.D.  
 ~ Dan Peterson, Echo Stenographer
- 10:00 – 10:30 **What Are You Doing to Me Neutropenia (Coronado Q)**  
*“What is a neutrophil, what does it do and how does it affect me? What is an absolute neutrophil count (ANC)? Why must I have so many blood tests?” These are common questions we hear from children. Dr. Steward will address these questions in an age-appropriate manner as well as address other concerns the boys may have.*  
 ~ Colin Steward, B.M., B.Ch., M.R.C.P., F.R.C.Pc.H., Ph.D.
- 10:30 – 10:45 **BREAK (Coronado M – T Lobby)**
- 10:45 – 11:45 **Being Left Behind (Coronado Q)**  
*Regardless of whether it is on a growth chart, running on the field or life in general, a common concern voiced by children with Barth syndrome is being left behind. Friends may not understand and in some cases eventually stop calling. These are some of the topics that will be addressed as well as ways to overcome these issues and be confident in your diversity.*  
 ~ Jules Spotts, Ph.D.  
 ~ Jacquie Butera, M.S.W., C.S.W., M.Ed
- 11:45 – 12:30 **Relationships With My Siblings (Coronado Q)**  
*Throughout history sibling relationships have been complete with love, rivalry, friendship and protection. Add to this mixture, healthy and extremely active children with chronically ill children and you have a new complex component. Boys will discuss these issues as well as having well-meaning over-protective sibs. How do I say...”not now I’m tired and don’t worry I’m fine” at the same time?*  
 ~ Jacquie Butera, M.S.W., C.S.W., M.Ed  
 ~ Jon Rosenshine, M.A., M.Ed.
- 12:30 – 13:30 **LUNCH (Coronado B - D)**
- 13:30 – 14:05 **Cardiology (El Paso 2)**  
*“What exactly is going on with my heart?” Boys will learn about common terms. They will also learn about the aspect of electrophysiology.*  
 ~ Barry Byrne, M.D., Ph.D.  
 ~ Randall Bryant, M.D.  
 ~ Carolyn Spencer, M.D.
- 14:05 – 14:45 **Genetics (El Paso 2)**  
*“How big is the TAZ gene and how does that affect me?” Boys will get hands-on skills with genetics.*  
 ~ Becky Kern, M.S., C.G.C.
- 14:45 – 15:00 **BREAK (Coronado M – T Lobby)**
- 15:00 – 16:00 **Group Activity (Banner and Puzzle) (El Paso 2)**  
 ~ B.J. Develle



**SUNDAY, JULY 11, 2004**

- 8:30 – 9:00 **CONTINENTAL BREAKFAST (Coronado M – T Lobby)**
- 9:00 – 9:45 **Education (El Paso 2)**  
*The record numbers of parent inquiries on the BSF listserv are on education. Boys will discuss the challenges they encounter in their educational endeavors.*  
~ Jon Rosenshine, M.A., M.Ed.
- 9:45 – 10:45 **Knowing When to Advocate for Myself (El Paso 2)**  
*A first step in the process of independence is knowing when one must advocate for himself. During this session children will discuss real life concerns and do some problem solving in the process.*  
~ Jon Rosenshine, M.A., M.Ed.
- 10:45 – 11:15 **What is BSF? (Coronado O)**  
*President of The Barth Syndrome Foundation will speak with this group to explain the activities of the group and expand on ways that siblings can get involved with the group. Every person in the family is affected by Barth syndrome, therefore every family member is also supported by BSF. Shelley will encourage siblings to “find their voice” within the group, working toward goals to better address the needs of siblings as well as ways that siblings can better support each other.*  
~ Valerie “Shelley” Bowen, President, Barth Syndrome Foundation
- 11:15 - 11:45 **I Am the Research and What Does it Mean? (El Paso 2)**  
*Many of these young men have participated in research studies throughout their lives. “How is science advancing? How will we benefit?”*  
~ Miriam Greenberg, Ph.D.
- 11:45 – 12:15 **Group Activity (Coronado Q)**  
~ Erika Frisby-Moore
- 12:15 – 13:30 **LUNCH (Coronado L)**
- 13:30 – 16:00 **Disney Quest Outing or BSF Activities in Suites with Group Leaders**  
~ **Must be accompanied by a parent or guardian for Disney Quest**  
~ *For individuals who will not be going to Disney Quest there will be group leaders remaining to work with siblings during this time.*

**MONDAY, JULY 12, 2004**

- 8:30 – 9:00 **CONTINENTAL BREAKFAST (Coronado A – G Lobby)**
- 9:00 – 10:00 **What Do I Have to Say? (Suite 1)**  
~ Jon Rosenshine, M.A., M.Ed.
- 10:00 – 11:45 **What Do I Have to Offer? (Suite 1)**  
~ Jon Rosenshine, M.A., M.Ed.
- 11:45 – 12:45 **LUNCH (Fiesta Ballroom)**
- 12:45 – 14:15 **Putting the Message Together (Suite 1)**  
~ Jon Rosenshine, M.A., M.Ed.
- 14:15 – 15:00 **Report to Group (Meeting with parents) (Durango 1 & 2)**  
~ Jon Rosenshine, M.A., M.Ed. or designate of the group

# **AGENDA FOR BARTH SYNDROME SIBLINGS AGES 12 – 15**

## **FRIDAY, JULY 9, 2004**

19:00 - 21:00 **Friday Night at the Movies (Acapulco)**

## **SATURDAY, JULY 10, 2004**

8:30 – 9:00 **CONTINENTAL BREAKFAST (Coronado M – T Lobby)**

9:00 – 9:15 **Welcome and Opening Remarks (Suite 2)**

*Aims of the weekend will be explained to the group as well as introductions of the group's participants  
~ Erika Frisby-Moore*

9:15 – 9:45 **People Just Don't Get It (Suite 2)**

*Barth syndrome doesn't just affect the boys and parents it also affects the siblings. Some of the common remarks we hear from our siblings in the group after they have grown up are "People just don't get it." "Why talk about something I don't even understand?" During this session children will discuss these issues.  
~ Jules Spotts, Ph.D.*

9:45 – 10:30 **Genetics (Suite 2)**

*Genetics will be explained in terms specific to the age group. Genetic counselor Becky Kern will explain the advances in genetics, the role of a genetic counselor in assisting families with a known genetic predisposition to Barth syndrome and aspects of diagnosis of genetic disorders in today's time with the ever progressing advances in genetic research.  
~ Becky Kern, MS, CGC*

10:30 – 10:45 **BREAK (Coronado M – T Lobby)**

10:45 – 12:30 **Sibling Support Project (El Paso 2)**

*Sibs aged twelve and older will join Don Meyer to meet other sibs, have some fun, play some great games and talk about the good - and not-so-good parts of having a brother with Barth syndrome with others who get it! Don is the Director of the Sibling Support Project and author and editor of many books on sibling issues.  
~ Don Meyer, Director*

12:30 – 13:30 **LUNCH (Coronado B - D)**

13:30 – 14:45 **Group Activity (Suite 3)**

*Projects have been planned for the various groups to present at the final meeting on Monday while all families are present. During this time the group will develop their presentation. They will work on the group project that will be presented during the Monday sessions.  
~ Erika Frisby-Moore*

14:45 – 15:00 **BREAK (Coronado M – T Lobby)**

15:00 – 16:00 **Chill Out Time (Suite 3)**

*~ Erika Frisby-Moore*

**SUNDAY, JULY 11, 2004**

- 8:30 – 9:00 **CONTINENTAL BREAKFAST (Coronado M – T Lobby)**
- 9:00 – 9:45 **What About my Education? (Coronado O)**  
*As children grow up with a brother who is chronically ill they have to learn at an early age to cope with day-to-day responsibilities such as school while worrying about their sibling. There are also the special occasions that sometimes seem overlooked. During this session we will work on healthy ways to share disappointment with parents and grandparents and family members who really do care a great deal.*  
~ Jacquie Butera, M.S.W., C.S.W., M.Ed
- 9:45 – 10:30 **How Do I Tell my Parents When Something is Bothering Me? (Coronado O)**  
*Open communication is key in any relationship. Growing up in a house with Barth syndrome just means that we may have different obstacles. All children are beloved parts of the family unit. During this session we will discuss the importance of sharing fears, concerns and yes, anger, in a productive manner.*  
~ Erika Frisby-Moore
- 10:30 – 10:45 **BREAK (Coronado M – T Lobby)**
- 10:45 – 11:45 **What is BSF? (Coronado O)**  
*President of The Barth Syndrome Foundation will speak with this group to explain the activities of the group and expand on ways that siblings can get involved with the group. Every person in the family is affected by Barth syndrome; therefore every family member is also supported by BSF. Shelley will encourage siblings to “find their voice” within the group, working toward goals to better address the needs of siblings as well as ways that siblings can better support each other.*  
~ Shelley Bowen, President, Barth Syndrome Foundation, Inc.
- 11:45 – 12:15 **Group Activity (Coronado O)**  
~ Erika Frisby-Moore
- 12:15 – 13:30 **LUNCH (Coronado L)**
- 13:30 – 16:00 **Disney Quest Outing or BSF Activities in suites with Group Leaders**  
**Must be accompanied by a parent or guardian for Disney Quest.**  
~ For individuals who will not be going to Disney Quest there will be group leaders remaining to work with siblings during this time.

**MONDAY, JULY 12, 2004**

- 8:30 – 9:00 **CONTINENTAL BREAKFAST (Coronado A – G Lobby)**
- 9:00 – 10:00 **What Do I Have To Say? (El Paso 2)**  
~ Erika Frisby-Moore
- 10:00 – 11:45 **What Do I Have To Offer? (El Paso 2)**  
~ Erika Frisby-Moore
- 11:45 – 12:45 **LUNCH (Fiesta Ballroom)**
- 12:45 – 14:15 **Pulling the Message Together (El Paso 2)**  
~ Erika Frisby-Moore
- 14:15 – 15:00 **Report to Group (Meeting with parents) (Durango 1 & 2)**  
~ Erika Frisby-Moore or designate of the group

# **AGENDA FOR BARTH SYNDROME BOYS AGE 16 AND UP**

## **FRIDAY, JULY 9, 2004**

19:00 - 21:00 **Friday Night at the Movies (Acapulco)**

## **SATURDAY, JULY 10, 2004**

8:00 – 9:00 **Photographs (Coronado M)**

8:30 – 9:00 **CONTINENTAL BREAKFAST (Coronado M – T Lobby)**

9:00 – 9:15 **Welcome and Opening Remarks (Coronado O)**

*Aims of the weekend will be explained to the group as well as introductions of the group's participants  
~ Jacquie Butera, M.S.W., C.S.W., M.Ed*

9:15 – 9:45 **What Are You Doing To Me Echo (Coronado O)**

*“What are they looking at when they do an echo on me? What are all of those lines and colors? What is the difference between an ejection fraction (EF) and a shortening fraction (SF)? How do you calculate the EF and the SF and what do they mean?” These are just some of the significant topics that will be addressed during this session. The mystery of the echocardiogram will be unveiled.  
~ Barry Byrne, M.D., Ph.D.  
~ Dan Peterson, Echo Stenographer*

9:45 – 10:00 **What Are You Doing to Me EKG (Coronado O)**

*Do you ever wonder what those peaks are on that shiny orange grid? During this session boys will learn what the different lines mean. “What is a P, Q, R, S, T other than letters of the alphabet and what do they mean?” How can you tell when mine looks different?”  
~ Barry Byrne, M.D., Ph.D.  
~ Dan Peterson, Echo Stenographer*

10:00 – 10:30 **What Are You Doing to Me Neutropenia (Coronado O)**

*“What is a neutrophil? What does it do and how does it affect me? What is an ANC? Why must I have so many blood tests?” These are common questions we hear from children. Dr. Steward will address these questions in an age appropriate manner as well as address further concerns the boys may have.  
~ Colin Steward, B.M., B.Ch., F.R.C.P., F.R.C.P.C.H., Ph.D.*

10:30 – 10:45 **BREAK (Coronado Lobby M - T)**

10:45 – 11:45 **Being Left Behind (Coronado O)**

*Regardless of whether it is on a growth chart, running on the field or life in general a common theme of children with Barth syndrome is the sentiment of being left behind. Friends may not understand and in some cases eventually stop calling. These are some of the topics that will be addressed as well as ways to overcome these issues and be confident in your diversity.  
~ Jules Spotts, Ph.D.  
~ Jacquie Butera, M.S.W., C.S.W., M.Ed*

11:45 – 12:30 **Relationships With My Siblings (Coronado O)**

*Throughout history sibling relationships have been complete with love, rivalry, friendship and shelter. Add to this mixture, healthy and extremely active children with chronically ill children and you have a new complex component. Boys will discuss these issues as well as having well-meaning over protective sibs. How do I say... “not now I'm tired and don't worry I'm fine” at the same time?  
~ Jacquie Butera, M.S.W., C.S.W., M.Ed  
~ Jon Rosenshine, M.A., M.Ed.*

- 12:30 – 13:30 **LUNCH (Coronado B - D)**
- 13:30 – 14:05 **Genetics (Coronado O)**  
*Learn about advances in genetics. “How big is the TAZ gene? Can Barth syndrome be diagnosed before a child is born? What is the difference between incidence and prevalence? How does that affect me?” Genetic Counselor Becky will also be doing some very cool hands-on experiments in genetics.*  
 ~ Becky Kern, M.S., C.G.C.
- 14:05 – 14:45 **Cardiology (Coronado Q)**  
*“What exactly is going on with my heart?” Boys will learn about terms such as dilated cardiomyopathy, hypertrophic cardiomyopathy, and left ventricle non-compaction. They will also learn about the aspect of electrophysiology.*  
 ~ Barry Byrne, M.D., Ph.D.  
 ~ Carolyn Spencer, M.D.  
 ~ Randall Bryant, M.D.
- 14:45 – 15:00 **BREAK (Coronado M – T Lobby)**
- 15:00 – 16:00 **Chill Out Time - Group Activity (Banner and Puzzle) (Suite 3)**  
 ~ B.J. Develle
- 15:00 – 16:00 **Issues with ICD for All Boys with ICD’s (Suite 2)**  
*Boys who have received an ICD will have the opportunity to discuss issues specifically pertaining to being a young person with an ICD. A time to address the industry will be available. Boys will develop a plan to advocate for the need to better address the concerns of a young person who has an ICD*  
 ~ Adrienne Kovacs, Ph.D.

**SUNDAY, JULY 11, 2004**

- 8:30 – 9:00 **CONTINENTAL BREAKFAST (Coronado M – T Lobby)**
- 9:00 – 10:30 **Update on Research (Family Sessions) (Durango 1 & 2)**
- 10:30 – 10:45 **BREAK (Coronado M - T)**
- 10:45 – 11:15 **Transitions (El Paso 2)**  
*Having Barth syndrome is difficult on every member of the family but certainly the most difficult on those affected by this disorder. As these young men mature into adulthood there are many transitions that occur while Barth syndrome remains a constant.*  
 ~ John Reiss, Ph.D.
- 11:15 – 11:45 **I Am the Research and What Does it Mean? (El Paso 2)**  
*Many of these young men have participated in research studies throughout their lives. “How is science advancing? How will we benefit?”*  
 ~ Miriam Greenberg, Ph.D.
- 11:45 – 12:15 **What is BSF? (El Paso 2)**  
*We will discuss advances with BSF and the role we would like to see these young men take in the future. Open discussion about age specific needs and creative solutions to address those needs.*  
 ~ Shelley Bowen, President, Barth Syndrome Foundation, Inc.
- 12:15 – 13:30 **LUNCH (Coronado L)**
- 13:30 – 16:00 **Disney Quest Outing or BSF Activities in suites with Group Leaders**  
**~ Must be accompanied by a parent or guardian for Disney Quest**  
 ~ For individuals not going to Disney Quest there will be group leaders remaining to work with siblings during this time.

**MONDAY, JULY 12, 2004**

- 8:30 – 9:00    **CONTINENTAL BREAKFAST** *(Coronado A – G Lobby)*
- 9:00 – 10:30   **What Do I Have to Say? What Do I Have to Offer?** *(Suite 2)*  
*Coming up with the final project identifying concerns of the siblings.*  
*~ Jacquie Butera, M.S.W., C.S.W., M.Ed*
- 10:30 - 10:45   **BREAK**
- 10:45 – 11:45   **What Do I Have to Say? What Do I Have to Offer?** *(Suite 2)*  
*Coming up with the final project identifying concerns of the siblings.*  
*~ Jacquie Butera, M.S.W., C.S.W., M.Ed*
- 11:45 – 12:45   **LUNCH** *(Fiesta Ballroom)*
- 12:45 – 14:15   **Pulling the Message Together** *(Suite 2)*  
*~ Jacquie Butera, M.S.W., C.S.W., M.Ed*
- 14:15 – 15:00   **Report to Group (Meeting with parents)** *(Suite 2)*  
*~ Jacquie Butera, M.S.W., C.S.W., M.Ed or Group Delegate*

**AGENDA FOR BARTH SYNDROME SIBLINGS AGES 16 AND UP**

**FRIDAY, JULY 9, 2004**

- 19:00 - 21:00   **Friday Night at the Movies** *(Acapulco)*

**SATURDAY, JULY 10, 2004**

- 8:30 – 9:00    **CONTINENTAL BREAKFAST** *(Coronado M – T Lobby)*
- 9:00 – 9:15    **Welcome and Opening Remarks** *(Suite 3)*  
*Aims of the weekend will be explained to the group as well as introductions of the group's participants*  
*~ Alanna Layton*
- 9:15 – 9:45    **Genetics** *(Suite 3)*  
*Genetics will be explained in terms specific to the age group. Genetic counselor Becky Kern will explain the advances in genetics, the role of a genetic counselor in assisting families with a known genetic pre-disposition to Barth syndrome and aspects of diagnosis of genetic disorders in today's time with the ever progressing advances in genetic research.*  
*~ Becky Kern, M.S., C.G.C.*
- 9:45 – 10:30   **The Longest Lasting Relationship** *(Suite 3)*  
*Psychologist Jules Spotts will facilitate this group. He will be addressing the issues siblings frequently encounter about their role in the continued management of children with Barth syndrome. "What happens when Mom and Dad are gone?"... "Who will take care of my brother?" Concerns of the siblings such as these and measures to make productive suggestions will be addressed during this session.*  
*~ Jules Spotts, Ph.D.*
- 10:30 – 10:45   **BREAK** *(Coronado M - T)*

10:45 – 12:30 **Sibling Support Project (El Paso 2)**  
*Sibs age sixteen and older will join Don Meyer to meet other sibs, have some fun, play some great games and talk about the good—and not-so-good parts of having a brother with Barth syndrome with others who get it! Don is the director of the Sibling Support Project and author and editor of many books on sibling issues.*  
~ Don Meyer, Director

12:30 – 13:30 **LUNCH (Coronado B - D)**

13:30 – 14:45 **Group Project (Banner and Puzzle) (Suite 3)**  
*Projects have been planned for the various groups to present at the final meeting on Monday while all families are present. During this time the group will develop their presentation. They will work on the group project that will be presented during the Monday sessions with Alanna Layton as the group leader.*  
~ Alanna Layton

14:45 – 15:00 **BREAK (Coronado M – T Ballroom)**

15:00 – 16:00 **Chill Out Time (Suite 3)**  
This will be down time to discuss the day's agenda

### **SUNDAY, JULY 11, 2004**

8:30 – 9:00 **CONTINENTAL BREAKFAST (Coronado M – T Lobby)**

9:00 – 10:30 **Update on Research (Family Sessions) (Durango 1 & 2)**  
*Siblings will attend the “Updates on Research” session with their families in Durango 2*

10:30 – 10:45 **BREAK (Coronado M – T Lobby)**

10:45 – 11:45 **What is BSF? (Coronado Q)**  
*President of The Barth Syndrome Foundation will speak with this group to explain the activities of the group and expand on ways that siblings can get involved with the group. Every person in the family is affected by Barth syndrome; therefore every family member is also supported by BSF. Shelley will encourage siblings to “find their voice” within the group, working toward goals to better address the needs of siblings as well as ways that siblings can better support each other.*  
~ Shelley Bowen, President, Barth Syndrome Foundation, Inc.

11:45 – 12:15 **Group Activity (Power Point) (Coronado Q)**  
Presentation for group meeting on Monday  
~ Alanna Layton

12:15 – 13:30 **LUNCH (Coronado L)**

13:30 – 16:00 **Disney Quest Outing or BSF Activities in suites with Group Leaders**  
**~ Must be accompanied by a parent or guardian for Disney Quest.**  
*~ For individuals who will not be going to Disney Quest there will be group leaders remaining to work with siblings during this time.*

**MONDAY, JULY 12, 2004**

8:30 – 9:00 **CONTINENTAL BREAKFAST** (*Coronado A – G Lobby*)

9:00 – 10:00 **What Do I Have to Say?** (*Suite 3*)  
*Coming up with the final project identifying concerns of the siblings.*  
*~Alanna Layton*

10:00 – 11:45 **What Do I Have to Offer?** (*Suite 3*)  
This is the time when siblings will come up with solutions they would like to suggest in addressing the specific concerns they have within their respective age group.  
*~ Alanna Layton*

11:45 – 12:45 **LUNCH** (*Fiesta Ballroom*)

12:45 – 14:15 **Pulling the Message Together** (*Suite 3*)  
*Final touches on the presentation and handouts.*  
*~ Alanna Layton*

14:15 – 15:00 **Report to Group (Meeting with parents)** (*Suite 3*)  
*~ Alanna Layton or designated sibling to present to the group.*

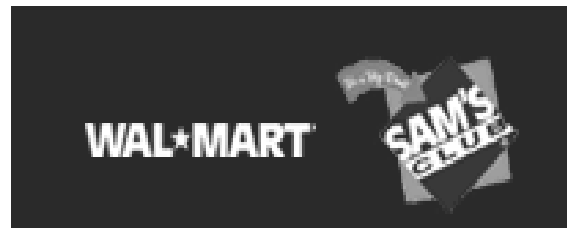


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## **BIBLIOGRAPHIES**



**Peter. G. Barth, M.D., Ph.D.** — Emeritus Professor in Pediatric Neurology; Emma Children's Hospital / AMC, Amsterdam, The Netherlands; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc.

*Dr. Barth is the pediatric neurologist who first described the condition that now bears his name, Barth syndrome. He is Co-founder of the Dutch Pediatric Neurology Society (1980). His previous research activities, in cooperation with Laboratories of Genetic Metabolic Diseases and Neurogenetics, include Barth syndrome, Peroxisome Biogenesis Disorders, and Neuro-degenerative disorders with prenatal onset. Dr. Barth officially retired in 2002, with retained activities in Barth syndrome, pontocerebellar hypoplasias and peroxisomal disorders.*

**Patricia Blanco, M.D.** — University Pediatrics, Sarasota, FL

*Dr. Blanco's pediatric practice is based out of Sarasota, Florida. Her interest in Barth syndrome came through caring for a child with the disorder. Dr. Blanco has a strong interest in educating parents to advocate for their children, thereby making them partners in care. She is empathetic to the needs of parents of children with chronically ill children. Dr. Blanco serves as the Assistant Medical Director of Children's Medical Services in Charlotte, Desoto, Manatee and Sarosota counties of Florida.*



**Mary Ann Bonilla, M.D.** — Assistant Professor, Department of Pediatrics, Columbia University, New York, NY; Consultant, Division of Pediatric Hematology Oncology, St. Joseph's Children's Hospital, Paterson, NJ; Advisory Board, Severe Chronic Neutropenia International Registry; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc.

*Dr. Bonilla was involved in conducting the initial clinical trials for G-CSF as a treatment for congenital neutropenia while at Memorial Sloan-Kettering Hospital. She is a pediatric hematologist oncologist who maintains an active interest in the treatment of white cell disorders, including Barth syndrome. As an Advisory Board member for the Severe Chronic Neutropenia International Registry, she has helped treat at least one Barth patient and has been involved with data concerning additional patients with Barth syndrome.*



**Valerie "Shelley" M. Bowen** — President, Barth Syndrome Foundation, Inc.

*Mrs. Bowen serves as the president of The Barth Syndrome Foundation as well as being a founding board member of the organization. She is the proud mother of Alanna, who is currently pursuing her Masters degree at The University of South Carolina and Michael, age 17 now a junior in high school. She also considers it a privilege to have been called mommy by Evan for a mere four years. Her current greatest personal challenges are home-schooling Michael through his high school years and pursuing a cure for the disorder that we all know as Barth syndrome. Through Shelley's personal experience of having two children with Barth syndrome she is committed to fundamental goals of The Barth Syndrome Foundation. Shelley has worked for 23 years in the dental field. She currently works as a management consultant in the field of dentistry.*





**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 is responsible for the analysis and interpretation of all viral PCR and genetic analysis testing results within the laboratory, as well as communicating that information and results to physicians, genetic counselors, and patients. Dr. Bowles' responsibilities, among others, include development and implementation of a laboratory database used for the storage of patient information and test results, report writing, and billing management; development of an automated sequencing assay for Barth syndrome; and development of assays to detect mitochondrial DNA point mutations, deletions, insertions, and depletions.*



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



**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 students 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 and 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. He completed his combined degree as a James Scholar at the University of Illinois before entering clinical training in pediatric cardiology and postdoctoral training*

*in biochemistry at Johns Hopkins University. His laboratory is engaged in a comprehensive research effort in molecular cardiology with emphasis on the diagnosis and treatment of heart failure in infants and children. The program is aimed at genetic therapy for treatment of inherited and acquired cardiovascular disease. As a model system, they are focusing on a fatal form of heart failure due to glycogen storage disease. These programs are being supported by the American Heart Association, Muscular Dystrophy Association, and the National Institutes of Health (NHLBI, NIDDK, and NCRR).*



**Rosalind A. Coleman, M.D.** — Associate Director, University of North Carolina Clinical Nutrition Research Center, Chapel Hill, NC; Director, Nutritional Biochemistry, Dept. Nutrition, University of North Carolina, Chapel Hill, NC; Professor, Departments of Nutrition and Pediatrics, University of North Carolina, Chapel Hill, NC

*Dr. Coleman's research studies include the metabolism of glycerolipids in the liver and Acyl-CoA synthetase - structure, function and regulation. She was also involved in the study of complex expression patterns of the Barth syndrome gene produce Tafazzin in human cell lines and murine tissues.*



**Gerald F. Cox, M.D., Ph.D.** — Medical Director, Department of Clinical Research, Genzyme Corporation, Cambridge, MA; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc.

*As a clinician in genetics, Dr. Cox has been involved in the care of several Barth patients. His particular interests include the genetic basis of cardiomyopathy and treatment of inborn errors of metabolism. In addition, he oversees clinical trials for a well-known biotechnology corporation.*



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

*Dr. Dale is a native of Knoxville, Tennessee. He trained in Internal Medicine at the Massachusetts General Hospital Boston and the University of Washington Medical Center, Seattle. During six years at the National Institutes of Health he developed a lasting interest in research on inflammation, neutrophils, and the clinical problem of neutropenia. He 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 & Europe

*Mrs. Damin is married to Marco and the mother of Nicholas and Matthew. She lives in Hampshire, UK, and is the Founding Member and Chairperson of the Barth Syndrome Trust (UK and Europe), an affiliation of The Barth Syndrome Foundation, Inc.*



**Anastasia "Stacie" Davis**

*Ms. Davis earned her Bachelor of Science degree majoring in Environmental Studies from Florida State University. She is currently employed with the Department of Environmental Protection as a project manager waste clean-up of the fragile Floridian ecosystem. Her commitment to BSF is as a result of her friendship with the Bowen family. She has seen first hand the struggles these children endure on a regular basis which has deepened her desire to support the cause.*



**Bruce Justin (B.J.) Develle**

*B.J. is a graduate of Florida State University, with a double major in Child Development and Religion. For the past 2 years, B.J. has been responsible for running a Therapeutic Foster Group Home in the Florida area. He is now employed as a Mental Health Case Manager and coordinates mental health services for children ages 4 through 17.*



**Greta Develle**

*Ms. Develle is excited to be a part of the Barth Syndrome Foundation conference this year as the group leader for the 8-11 year old siblings. She is originally from the suburbs of Chicago, Illinois and graduated with a Bachelor of Science degree in Applied Math from Florida State University (FSU) in 2002. She currently works as a web programmer and coordinator of information technology for FSU in the Information Management Team, a division of the Office of Admissions and Records.*



**Anna Dunn**— Vice President and Family Liaison, Barth Syndrome Foundation, Inc.

*Mrs. Dunn is a founding member of the Barth Syndrome Foundation, Inc. (BSF) Board of Directors and serves as Vice President and Family Liaison. She has a nursing education and lives in Franklin, Massachusetts with her husband Mark, and their three boys Armando (14), Aldo (11) and Angelo (10). Her passion has been and continues to be in BSF, specifically serving the needs of the Barth families.*



**William Dowhan, Ph.D.**— Professor, Department of Biochemistry and Molecular Biology, Department of Microbiology and Molecular Genetics, The University of Texas-Houston Medical School, Houston, TX

*Dr. Dowhan is a professor and holder of the John S. Dunn, Sr. Chair of Biochemistry and Molecular Biology. Currently he is involved in the combined molecular genetic and biochemical approach which is being used to study the structure, function, and biogenesis of biological membranes in prokaryotic (*E. coli*) and eukaryotic (yeast) microorganisms as well as in mammalian cells. Studies utilizing *E. coli* focus on understanding biological processes which are similar in both simple and complex organisms. A major goal is to understand the role individual phospholipid species and general membrane phospholipid composition play in cell function. Particular emphasis is being placed on understanding the specific roles of anionic phospholipids in normal mitochondrial function and biogenesis.*



**Lynn Elwood, Secretary**— The Barth Syndrome Foundation, Canada

*Mrs. Elwood is a founding board member of the Barth Syndrome Foundation Canada and is passionately involved with the Barth Syndrome Foundation's initiatives, including the operation of the website and other awareness activities. Lynn, her Barth son Adam (14), husband Rick, and unaffected son Justin (7) live in Toronto, Ontario. Lynn's other activities include a full-time position as Director of Research & Development for Hummingbird Inc. She is also a black belt in Karate and produces her cottage association website and newsletter.*



**Mauro Degli Esposti**— Lecturer in Molecular Toxicology, School of Biological Sciences, University of Manchester, United Kingdom

*Mauro Degli Esposti has worked in 4 countries on 3 different continents. Born and educated in Italy, he became a young blood Lecturer at the Department of Biology of the University of Bologna. Intermittently with academic duties in Bologna, he spent various Post Doc periods in the States (mostly at Rice University, Houston). In the 90's, he moved to Melbourne, Australia and worked as Senior Research Fellow at Monash University. Subsequently he visited research institutes in San Diego, where he learnt all the tricks of apoptosis. He began to work in Manchester, UK at the turn of this new millennium, recently assuming the position of Lecturer in Molecular Toxicology. He is building a very active, competitive team – the Mitochondrial Apoptosis Group – which conjugates hard work with social events to reinforce the feeling that research is also fun!*



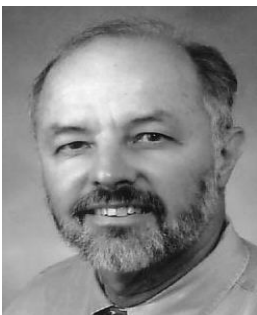
**John Fakunding, Ph.D.**— Director, Heart Research Program, Division of Heart and Vascular Diseases, National Heart, Lung, and Blood Institute, National Institutes of Health, Bethesda, MD

*Dr. Fakunding received his Ph.D. degree in biochemistry from the University of California at Davis and completed postdoctoral training at Baylor College of Medicine in Houston, Texas. He oversees a large extramural grant program spanning the spectrum from congenital heart disease to heart failure. In addition to having a perspective on research involving diseases of the myocardium, he has developed specific interests in cell-based therapies for heart disease. During his years at the NIH, Dr. Fakunding has gained a unique perspective on the role of NIH in stimulating and managing biomedical research.*



**Annette Feigenbaum, M.D., Ch.B., F.R.C.P.C.** — Division of Clinical and Metabolic Genetics, The Hospital for Sick Children; Assistant Professor, Department of Pediatrics, University of Toronto, Toronto, Ontario, Canada; Scientific and Medical Advisory Board, The Barth Syndrome Foundation, Inc.

*Dr. Feigenbaum is a South African trained pediatrician. Since 1992 she has been on full-time active clinical staff at The Hospital for Sick Children Toronto, Canada. Her main focus is clinical management of patients with inborn errors of metabolism and she has extensive experience at one of the largest centers in North America dedicated to this. She trained as a Clinical Fellow in Clinical and Metabolic Genetics, then as a Medical Research Council of Canada Postdoctoral Laboratory Research Fellow for 4 years including 3 years studying mitochondrial diseases. She has a special interest in children with mitochondrial diseases including Barth syndrome. Dr. Feigenbaum provides medical care, consultative service and genetic counseling for families, children and adults with metabolic diseases. She serves on the Medical and Scientific Advisory Board of the Barth Syndrome Foundation and the United Mitochondrial Disease Foundation (UMDF).*



**Frederick J. Fricker, M.D.**— Professor and Chief, Division of Cardiology, Department of Pediatrics, University of Florida College of Medicine; Eminent Scholar, Gerold L. Schiebler Eminent Scholar Chair in Pediatric Cardiology, University of Florida College of Medicine, Gainesville, FL

*Dr. Fricker is a professor and chief of the Division of Pediatric Cardiology in the Department of Pediatrics. He is also the recipient of the Gerold L. Schiebler Eminent Scholar Chair in Pediatric Cardiology. His primary focus is in heart and heart lung transplantation, and he is nationally and internationally known in the field of Pediatric Thoracic and Organ Transplantation. He has been instrumental in developing a successful Pediatric Cardiology Program encompassing divisions based in both Gainesville and Jacksonville.*



**Erika Frisby-Moore**

*Erika Frisby-Moore graduated from Cumberland College with a degree in Psychology. Currently she lives in her home town of Tallahassee, Florida and works in child protection. Previously, she has worked with at-risk youth in a residential facility and in a school setting. Erika celebrated her first year of marriage this past February, and she and her husband recently learned that they are expecting an addition to their family. This is Erika's first year as a group leader for this conference, and she is greatly looking forward to working with her group and their families.*





**Paula Richley Geigle, P.T., Ph.D., NCCAM Postdoctoral Fellow** — Adjunct Faculty of Physical Therapy, Arcadia University; NCCAM Postdoctoral Fellow, University of Pennsylvania Medical School, Philadelphia, PA

*Dr. Geigle is an adjunct faculty member of physical therapy at Arcadia University and currently is completing a two year postdoctoral training through the University of Pennsylvania Medical School Center for Clinical Epidemiology and Biostatistics (CCEB). She demonstrates 6 years of clinical CAM research experience and 20+ clinical years, mainly in the movement areas. Dr. Geigle is active in clinical practice and research arenas and currently serves as President of the Aquatic Physical Therapy Section of the American Physical Therapy Association. She is a seasoned physical therapy educator explicitly interested in teaching clinical decision-making. Doctoral social science preparation and research included equal components of quantitative and qualitative assessment. Quality of life (QOL) issues have always been a personal clinical focus for Dr. Geigle and during her fellowship she was able to increase understanding of potential QOL research methods and data analysis possibilities.*



**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.

*As a molecular geneticist in a diagnostic lab, Dr. Gonzalez 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.*



**Carolyn Gravitt** — Registered Health Information Administrator, Precyse Solutions, Chattanooga, TN

*Ms. Gravitt has 25 years experience in medical record management. Currently she is Senior Consultant with Precyse Solutions, a recognized leader in health information management. Carolyn has one son, David Mann, a lovely daughter-in-law, Shelia Mann, a granddaughter, English Mann, and a grandson, Benjamin Mann who has Barth Syndrome. She lives in Chattanooga, Tennessee and travels throughout the US in her profession.*



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

*Dr. Greenberg's well-known research interests focus on genetic control of mitochondrial membrane biogenesis in yeast, in particular. How newly synthesized lipids and proteins are integrated into the membranes of specific organelles is a central question in organelle biogenesis.*



**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.*



**Kristen Johnson**

*Ms. Johnson is a native of Snellville, Georgia. She graduated from the College of Charleston in Charleston, South Carolina with a degree in Media Studies. A member of Kappa Delta sorority, Kristen participated in many charity events benefiting the sorority's chosen philanthropies, which included the Lowcountry Children's Center, Girl Scouts USA, and Prevent Child Abuse America. She currently is pursuing a Masters Degree in Mass Communication at the University of South Carolina, and in her spare time she enjoys writing, painting, and volunteering.*



**Eileen O. Juico, M.A., M.Ed.**— Learning Specialist, Rye Country Day School, Rye, NY

*Ms. Juico's first masters is in curriculum and instruction from Loyola University in Chicago and her second is in special education from New York University. She was a special education teacher in two New York City elementary schools and also taught study skills for a few years at the Riverdale Country School. Ms. Juico then moved to Atlanta where she started a program for students with learning differences in grades 7-12. She currently works at a private school in New York where she provides additional academic support to students. She collaborates with the counselor, Jacquie Butera, to assist those individuals with a variety of challenges from academic, to physical, to emotional. Ms. Juico began working with a student with Barth syndrome three years ago, and his courage and determination inspired her to become more involved with the Barth Syndrome Foundation.*



**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 an expert in metabolic diseases and has been involved in the treatment of more cases of Barth syndrome than any other individual in the US. He hosted the first International Scientific and Family Conference on Barth Syndrome in June 2000 at Johns Hopkins' Kennedy Krieger Institute and has been Chairman of the Barth Syndrome Foundation's Scientific Medical Advisory Board since its inception.*



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

*Ms. Kern is a graduate of the University of Maryland, Baltimore School of Medicine Master's in Genetic Counseling Program. She joined Dr. Kelley's team at Kennedy Krieger Institute in July of 2002. One of her primary roles is to assist with both clinical care and research involving families with Barth syndrome. Other interests include new technologies and education relevant to newborn screening, preimplantation genetic diagnosis for single gene disorders, and neuropsychiatric genetics.*



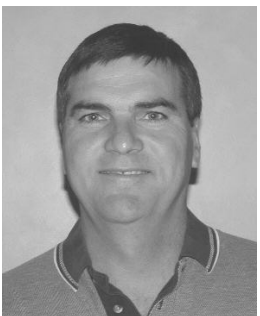
**Adrienne Kovacs, Ph.D.**— Postdoctoral Associate, Department of Clinical & Health Psychology, University of Florida, Gainesville, FL

*Dr. Kovacs is currently a postdoctoral associate in the Department of Clinical & Health Psychology at the University of Florida. Her focus is the enhanced quality of life of cardiac patients and the promotion of healthy lifestyle behaviors. Current specific interests include coping with implantable cardioverter defibrillators (ICDs) and the psychosocial adjustment of adults with congenital heart defects. She provides clinical services to cardiac patients and serves as project manager on grant-funded cardiac research projects.*



**Jan Kugelmann**— Fundraising Committee, Barth Syndrome Foundation, Inc.

*Mrs. Kugelmann resides in Merritt Island, Florida with her husband of 21 years, Steve. They have two children, Elizabeth Lee, 11 and Robert Jack (R.J.) 6, 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 and serves as the grassroots fundraising coordinator for the foundation, in addition to hosting an annual golf tournament benefiting the foundation.*



**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 lead design engineer for the Space Shuttle program. He has been married to Jan for 21 years and has two children, Elizabeth Lee, 11 and Robert Jack (R.J.), 6, 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.*



**Alanna Layton**

*Ms. Layton, the daughter of Shelley and Michael Bowen and sister of Michael, serves as the Sibling Support Director for The Barth Syndrome Foundation. Alanna received her Bachelor of Arts Degree in Creative Writing from Florida State University in 2002. She is currently hard at work earning a Master of Mass Communications degree from the University of South Carolina.*



**David Mann**— Fundraising Committee, The Barth Syndrome Foundation, Inc.

*Mr. Mann has a Bachelor of Science degree in Human Ecology and is currently a sanitation manager for Travis Meats, Inc., in Knoxville, TN. He is married and the father of two children, ages 11 and 7. His 7-year-old boy has Barth Syndrome.*



**Shelia C. Mann, R.D.H.**— Family Support Services Program Coordinator, The Barth Syndrome Foundation, Inc.

*Ms. Mann is a registered dental hygienist in Chattanooga, TN. She is married to David and the mother of two children, ages 11 and 7. Her 7-year-old boy has Barth Syndrome. She also serves as a parent teacher for Project D.O.C.C. (Delivery of Chronic Care) program in Chattanooga, TN.*



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

*Mrs. McCurdy is a founding member of The Barth Syndrome Foundation, Inc.'s (BSF) Board of Directors and serves as the Vice President of Science and Medicine. She has an MBA from the Harvard Business School and has held various positions on the Boards of several other nonprofit organizations. Her most important credential, however, comes from being the mother of a wonderful 18-year old son with Barth syndrome. She is strongly 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 (18 years old) and Eliza (nine years old), and married to Kate McCurdy. He is a founding Board Member and Chief Financial Officer of the Barth Syndrome Foundation, Inc. He is a graduate of the Harvard Business School and currently is employed by American Express in New York City. The McCurdy's live in Larchmont, New York.*



**Donald Meyer**— Director, The Arc of the United States' Sibling Support Project, Seattle, WA

*Mr. Meyer has conducted more than 200 workshops throughout the United States, Canada, Ireland, England, New Zealand and Japan, training over 8,000 parents and providers on sibling issues and the Sibshop model. He was a founder of the SEFAM (Supporting Extended Family Members) program at the University of Washington, which pioneered services for fathers, siblings, and grandparents of children with special needs. He is the senior author and editor of four books: Sibshops: Workshops for brothers and sisters of children with special needs; Uncommon Fathers: Reflections on Raising a Child with Special Needs; and the children's books Living with a Brother or Sister with Special Needs: a Book for Sibs and Views from our Shoes Growing up with a brother or sister with special needs.*



**Thomas D. Monahan**— Fundraising Committee, Barth Syndrome Foundation, Inc.

*Mr. Monahan lives in Brockton, Massachusetts where he has worked at Bay State Gas Company in the Maps and Records Department for 23 years. He is a commissioner on the Brockton Parks and Recreation Department. He is also involved in coaching youth hockey, and enjoys playing hockey, softball, and basketball. Along with his wife Laurie they have five children, Jennifer, age 23, Tom, age 21 and a Member of the U.S. Marine Corps, Mike, age 19, Dan, age 17 and Timmy, age 14 (Barth syndrome).*



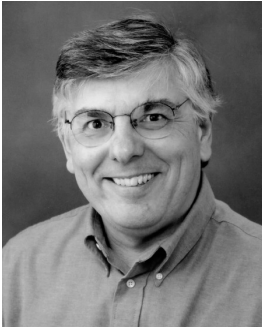
**Susan Old, Ph.D.** — Associate Director, Clinical and Molecular Medicine Program, National Heart, Lung and Blood Institute, NIH, Bethesda, MD

*Dr. Old received her Ph.D. in 1987 from the Department of Human Genetics, University of Michigan in Ann Arbor. She completed her postdoctoral training in New York as a Research Fellow at Columbia University in the Division of Pediatric Neurology. Dr. Old transferred to the National Heart, Lung, and Blood Institute (NHLBI), part of the NIH, as a Health Scientist Administrator in the Division of Heart and Vascular Diseases (DHVD) where she quickly put her combination of scientific expertise in genetics, administrative skills, and her leadership ability to work, planning, developing, and managing large, complex research programs. She has had primary responsibility for the NHLBI Programs for Genomics Applications (PGA), the NHLBI Family Blood Pressure Program, the Mammalian Genotyping Service, the Rat Genome Project, and the NHLBI Proteomics Initiative. In 2002, Dr. Old was selected as the Program Leader for the Bioengineering and Genomic Applications Research Program (BGA) in DHVD. This program is responsible for overseeing a diverse portfolio of extramural research grants and contracts involving genetics, genomics, proteomics, bioinformatics/computational biology, tissue engineering, bioimaging and bioengineering. Dr. Old is currently the Associate Director for the Clinical and Molecular Medicine Program which guides the BGA and the Cardiovascular Medicine Research Group. In addition to her duties at the NHLBI, Dr. Old is a frequent speaker, providing advice to other NIH Institutes and organizations on implementing programs in genetics, genomics, and proteomics and in managing large, diverse research programs.*



**Tyler Reimschisel, M.D.** — Chief Resident, Genetic Medicine, The Johns Hopkins Hospital, Baltimore, MD

*Dr. Reimschisel graduated from Rush Medical College in 1997. He completed residency training in pediatrics and pediatric neurology at Johns Hopkins University School of Medicine. He is currently the Chief Resident in Genetic Medicine at Johns Hopkins Hospital and is completing his last year of training in clinical genetics. His primary areas of interest include biochemical genetics, the neurologic manifestations of genetic diseases, and clinical ethics. He has published 3 journal articles and 4 book chapters.*



**John Reiss, Ph.D.** — Chief, Division of Policy and Program Affairs, Institute for Child Health Policy; and Associate Professor of Pediatrics and of Epidemiology & Health Policy at the University of Florida, Gainesville, Florida

*Over the last 15 years, Dr. Reiss' work has focused on facilitating collaborative action among public and private sector organizations at the federal, regional, and state, 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. In 1998, He began his work on the issue of health care transition as part of the federally funded Center for Policy and Program Partnerships. The mission of this Center was, in part, to support implementation of MCHB national "Healthy and Ready to Work" transition initiative. Currently, Dr. Reiss is the PI for three health care transition projects: a five-year NIDRR funded research and training project on the transition of youth with special health needs from child-centered (pediatric) to adult-oriented health care; a one year contract from the Florida Children's Medical Services Program to develop a Web-based Health Care Transition training curriculum for CMS nurses; and a one year contract from the Florida Developmental Disabilities Council to develop web-based HCT training materials for families and youth. Through the NIDRR grant, Dr. Reiss also moderates a special interest e-mail discussion group, which has more than 1600 members, internationally.*



**Catharine L. Ritter** — President, Barth Syndrome Foundation, Canada

*Like many here, Mrs. Ritter's entire life has been affected by Barth syndrome first in her early years with the loss of a cousin and a brother and later on in life with the death of her son Shawn. This led her to believe that something was going on in the family and sought genetic counseling which led to the diagnosis of Barth syndrome. A few months after this diagnosis Ryan, who is currently 13 and also affected by Barth, joined his older sister Stephanie and unaffected brother Andrew in the Ritter household. It was after the 2002 conference in Baltimore that she and some fellow Canadians decided to form the Barth Syndrome Foundation of Canada of which she is an acting board member. Mrs. Ritter is a registered nurse by profession specializing in sick and premature newborn infants. She has been married to her high school sweetheart Chris for 25 years and in her spare time enjoys working in her garden in Utopia, Ontario or relaxing at the cottage with family.*



**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 taught English in several of the top schools in the New York City area. Recently, he received a grant from The Barth Syndrome Foundation, Inc. to conduct research into the social, emotional, neurodevelopmental, health and legal issues concerning the education of children affected by Barth syndrome. He is writing and overseeing the printing of four handbooks for families and educators to help facilitate the education of and advocacy for the Barth syndrome students.*



**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.*



**Raghad Schroeder, O.T.R./L.**— Theraplay PLLC, Clifton Park, NY

*Ms. Schroeder is a graduate of the State University of New York at Buffalo's Occupational Therapy program. She has 23 years of clinical experience in rehabilitation and pediatrics. Raghad specializes in evaluation and treatments of neonates to elementary school age children. Her interests are in neurological and orthopedic based therapy, sensory integration evaluation and treatment and feeding/swallowing techniques. Raghad is co-owner of Theraplay PLLC, a pediatric occupational and physical therapy practice in Clifton Park, NY. She is the mom of 3 awesome teen-agers.*



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

*Ms. Sedefian, Mom of Eric (deceased), Justin (14 years old) and Derek (11), serves on The Barth Syndrome Foundation, Inc.'s (BSF) Board of Directors. She also has the honor of coordinating and designing BSF's printed materials (newsletters, brochures, programs, business cards, etc.) Born in Albany, NY, Ms. Sedefian worked for the NYS Departments of Law and Health as a Senior Stenographer for ten years prior to leaving service to stay at home with her children.*



**Ariel 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, Division of Pediatric Cardiology, University of Florida College of Medicine, Department of Pediatrics (Cardiology), Gainesville, FL; Fellow, Non-invasive Laboratory, Department of Cardiology, Children’s Hospital Boston,

*Dr. Spencer is the director of Pediatric Echocardiography at the University of Florida. Her particular interests include echo-cardiography and management of heart failure as well as adults with congenital heart disease.*



**Jules Spotts, Ph.D., P.C.**— Independent Psychotherapy Practice, New Canaan, CT; Consultant, New Canaan Country School, New Canaan, CT; Consultant, The Hewitt School, New York, NY

*Dr. Spotts is a clinical psychologist who has a private practice in Connecticut and who also provides a broad range of mental health services at several private schools located in the New York and Connecticut areas.*



**Colin G. Steward, B.M., B.Ch., M.R.C.P., F.R.C.Pc.H., Ph.D.**— Bristol Royal Hospital for Sick Children, Bristol, UK

*Dr Steward is Reader in Stem Cell Transplantation at the University of Bristol, England and is interested in genetic diseases affecting the blood and bone marrow. 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 has recently organized a specialist clinic 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.*





**Joan C. Stoner, Ed. D.**— Assistant Director and Professional Development Team - Early Reading First Grant, Toppeka, KS; Adjunct Faculty, Department of Special Education, University of Nebraska, Lincoln, NE; Board Chair, Capella University, an all internet university that is North Central Accredited with administrative offices located in Minneapolis, MN; Educational Consultant, The Barth Syndrome Foundation, Inc.

*Dr. Stoner was a Learning Disabilities Specialist at the Menninger Center for Learning Disabilities. She developed The Center for Learning Disabilities to prepare teachers to implement a mandated program for students with dyslexia in the state of Louisiana. Dr. Stoner has established two college programs for dyslexic students and taught dyslexic students at all levels. Dr. Stoner earned the Ed.D. in Administration, Curriculum and Supervision from the University of Nebraska-Lincoln.*



**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.*



**Frederic Vaz, Ph.D.**— Post-Doctoral Fellow, Laboratory of Genetic Metabolic Disease, University of Amsterdam, Amsterdam, The Netherlands

*Dr. Vaz is a Post-Doctoral Fellow in the Laboratory of Genetic Metabolic Disease at the University of Amsterdam. His research studies into the "Resolution of the Function of the TAZ-gene and Characterization of its Gene Products" (supported by The Barth Syndrome Foundation), aims to determine the exact function of Tafazzin. In addition, Dr. Vaz is in the process of ameliorating assays to accurately diagnose Barth syndrome on the basis of the cardioplipin profile.*



**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 (22 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.*



**Cindy Yang Xu, M.D., Ph.D.**— Research Assistant Scientist, Department of Anesthesiology, New York University School of Medicine, New York, NY

*Dr. Yang Xu works along side Dr. Michael Schlame and is involved in the research of cardioplipin remodeling by phospholipid transacylation; in particular the suggestion that phospholipid transacylation (transfer of fatty acyl residues between phospholipids) is involved in the generation of specific fatty acid profiles in mitochondrial cardioplipin. The present proposal is designed to test the hypothesis that tafazzin is a phospholipid transacylase.*

**CLINICS/RESEARCH STUDIES**

**Cardiology**

Barry J. Byrne, M.D., Ph.D.  
Carolyn T. Spencer, M.D.  
Randall M. Bryant, M.D.  
Sharon Redfearn, A.R.N.P.  
Jane Day, Ph.D.  
Julie Berthy, A.R.N.P.  
Debbie Pruett, R.D.C.S.  
Sharon Chapman, R.D.C.S.

**CPR**

Debbie Kacinski

**Neurology**

Tyler Reimschisel, M.D.

**Occupational Therapy/Physical Therapy**

Raghad Schroeder, O.T.R./L.  
Paula Geigle, Ph.D., P.T., M.C.C.A.M.

**Math Skills Development Project**

Michele Mazzocco, Ph.D.  
Anne Henry, Research Assistant

**Vitals Training**

Linda Croxton, A.R.N.P.

**CONSULTATIONS**

**Education**

Jonathan Rosenshine, M.A., M.Ed.  
Joan C. Stoner, Ed.D.  
Eileen Q. Juico, M.A., M.Ed.  
Jaclyn M. Butera, M.S.W., C.S.W., M.Ed.

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Iris Gonzalez, Ph.D.  
Rebecca Kern, M.G.C.

**Neurology**

Tyler Reimschisel, M.D.

**Occupational Therapy/Physical Therapy**

Raghad Schroeder, O.T.R./L.  
Paula Geigle, Ph.D., P.T., M.C.C.A.M.

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