

**Barth Syndrome Foundation
6th International Scientific, Medical & Family Conference**

X Marks the Spot for a Cure!

**June 25-30, 2012
St. Pete Beach, FL**

The Scientific and Medical sessions will be held on Thursday and Friday, June 28-29 and will feature the following speakers and programs:

Conference Organizers:

Michael Schlame, MD--Associate Professor, New York University Medical Center, New York, NY

Barry J. Byrne, MD, PhD--Associate Chair & Professor, University of Florida, Gainesville, FL

Grant Hatch, PhD--Professor, University of Manitoba, Winnipeg, Canada

Richard Kelley, MD, PhD--Professor, Kennedy Krieger Institute, Johns Hopkins University, Baltimore, MD

Matthew J. Toth, PhD--Science Director, Barth Syndrome Foundation, Inc.

Session I -- Thursday AM, June 28, 2012

Clinical Aspects and Epidemiology of Barth Syndrome

Chair: Richard Kelley, MD, PhD, Professor, Kennedy Krieger Institute, Johns Hopkins University, Baltimore, MD

Speakers:

Richard Kelley, MD, PhD, Kennedy Krieger Institute, Johns Hopkins University, Baltimore, MD

Colin Steward, FRCP, FRCPCH, PhD, Bristol Royal Hospital for Children, Bristol, UK

W. Todd Cade, PT, PhD, Washington University, St. Louis, MO

Keynote Speaker (*Thursday Luncheon*)

A Globalization of Rare Diseases Research Activities.

Stephen C. Groft, Pharm D, Director of the Office of Rare Disease Research (ORDR), NIH, Bethesda, MD

BSF is very pleased to announce that the Director of the Office of Rare Disease Research (ORDR), Stephen C. Groft, Pharm.D, will be the keynote speaker at BSF's 2012 Conference. Dr. Groft has been one of the most enthusiastic supporters of the BSF, and his department has been very generous in financially supporting our biennial conferences. As of December 23, 2011, the ORDR now reports to National Center for Advancing Translational Sciences. The BSF is greatly appreciative of the NIH, and of the ORDR in particular, for their help and advice over the years. We look forward to hearing Dr. Groft's ideas about the future of rare disease research.

Session II --Thursday PM, June 28, 2012

Biological Function of Tafazzin and Cardiolipin

Chair: Grant Hatch, PhD, Professor, University of Manitoba, Winnipeg, Canada

Speakers:

Steven M. Claypool, PhD, Johns Hopkins University, Baltimore, MD
Miriam L. Greenberg, PhD, Wayne State University, Detroit, MI
Frederick M. Vaz, PhD, Academic Medical Center, Amsterdam, The Netherlands
Michael Schlame, MD, New York University Medical Center, New York, NY
Christopher McMaster, PhD, Dalhousie University, Halifax, Canada

Session III -- Friday AM, June 29, 2012

Mouse Model of Barth Syndrome

Chair: Michael Schlame, MD, New York University Medical Center, New York, NY

Speakers:

John L. Jefferies, MD, MPH, Cincinnati Children's Medical Center, Cincinnati, OH
Colin K. Phoon, MPhil, MD, New York University, New York, NY
Meghan Soustek, University of Florida, Gainesville, FL
Zaza Khuchua, PhD, Children's Hospital Medical Center, Cincinnati, OH
Michael Kiebish, PhD, Washington University, St. Louis, MO
Adam J. Chicco, PhD, Colorado State University, Fort Collins, CO

Session IV -- Friday PM, June 29, 2012

Mitochondrial Physiology of Barth Syndrome

Chair: Grant Hatch, PhD, Professor, University of Manitoba, Winnipeg, Canada

Speakers:

Two poster session presenters chosen by Conference Chairs
Mindong Ren, PhD, New York University, New York, NY
Grant Hatch, PhD, University of Manitoba, Winnipeg, Canada
Anton I. De Kroon, PhD, Utrecht University, Utrecht, The Netherlands
William Pu, MD, Children's Hospital Boston, Boston, MA
Yuguang (Roger) Shi, PhD, Penn State University College of Medicine, Hershey, PA

Overview

	Science & Medicine Sessions	Family Sessions
Monday June 25		Registration & Welcome Ceremony
Tuesday & Wednesday June 26-27	Patient Discussions <i>(by invitation)</i>	Discussions with BTHS experts and Research Studies (formerly called "Clinics")
Wednesday Evening June 27	Physician/Scientist Registration & Informal Reception	
Thursday & Friday June 28-29	Scientific-Medical Sessions Poster Session <i>(Thursday)</i>	Family/BTHS Individual/Sibling Sessions
Saturday June 30	SMAB Meeting <i>(by invitation)</i> Closing Ceremony	Breakouts Closing Ceremony