

Course Overview

Worldwide, Friedreich's Ataxia (FA) affects roughly one in 50,000 people, making it the most common in a group of related disorders called hereditary ataxias. While there is currently no cure for FA, efforts continue to be made towards research that will one day halt or even reverse disease progression. The Friedreich's Ataxia Program at The Children's Hospital of Philadelphia is pleased to present this one-day symposium providing patients and families with up to date clinical information, therapeutic approaches and current research being conducted in the field of Friedreich's Ataxia.

General Information

The conference will be held on the first floor of the Leonard and Madlyn Abramson Pediatric Research Building located on the Children's Hospital of Philadelphia main campus. Registration will begin at 8:15 a.m. Registration fee includes course materials, continental breakfast, refreshments, lunch and parking.

Registration Information

Attendees can register by mail, fax or online. Please see the registration form for the address, fax and web address. Pre-registration is required and the registration deadline is November 21, 2008. Payment must accompany registration form for it to be processed. Once registration has been processed a confirmation letter will be mailed or faxed.

PLEASE NOTE: Registration is not complete if you do not receive this confirmation. If you do not receive a confirmation within 10 days of registration, please contact us at (215) 590 - 5263.

Hotel Information

A block of rooms has been reserved at reduced rates at The Inn at Penn, located within walking distance from Children's Hospital and the University of Pennsylvania's bustling campus. There is upscale shopping, dining and nightlife as well as convenient access to Center City Philadelphia, Amtrak's 30th Street Station, I-76 and the Philadelphia International Airport.

The group rate is \$214 single and double occupancy plus a 14 percent room tax. Participants are required to reserve their own hotel accommodations by calling The Inn at Penn directly at 215-222-0200. Please mention the name of the conference when making your reservation. The special room rate will be available until October 22, 2008. After that date, reservations will be accepted according to space and rate availability.

Cancellation and Refund Policy

The Children's Hospital of Philadelphia reserves the right to cancel or postpone any course due to any unforeseen circumstances. In the event of cancellation or postponement, The Children's Hospital of Philadelphia will refund any registration fees, but is not responsible for any related costs, charges or expenses to participants, including cancellation charges assessed by hotel, airlines/travel agencies.

In order to process refunds for course withdrawals, cancellations must be received in writing by November 28, 2008. No refunds will be issued thereafter. Refunds will be issued for the amount of registration minus a \$40 service charge.

Services for the Disabled

If special arrangements are required for an individual with a disability to attend this meeting, please contact the Continuing Medical Education Department at 215-590-5263.

About Philadelphia

Welcome to Philadelphia, the place that loves you back! The fifth largest city in the United States, Philadelphia is one of the world's most dynamic destinations. In Philadelphia, you will be at the crossroads of big city excitement and hometown hospitality, where the promise of the future meets old-world charm. Most famous as the birthplace of American independence and home the Liberty Bell and National Constitution Center, Philadelphia offers a unique variety of attractions, culture and entertainment. For more information: www.pcvb.com or www.gophila.com

Program

- 8:15 a.m. Registration and Continental Breakfast**
- 8:50 a.m. Welcome and Introduction**
David Lynch, M.D., Ph.D.
- 9 a.m. To Hell With The Wheel Chair, Let's Go Have Fun!**
Gavin Kerr
Dynah Haubert
Kyle Bryant
- 10 a.m. What your Primary Care Provider Should Know About Friedreich's Ataxia**
David Lynch, M.D., Ph.D.
- 10:30 a.m. Break and Exhibits**
- 11 a.m. Pathway to Clinical Trials & Realities of Drug Development**
Jennifer M. Farmer, M.S., C.G.C.
- 11:30 a.m. Cardiac Dysfunction in Friedreich's Ataxia**
Martin G. St. John Sutton, M.B.B.S
- 12:15 p.m. Imagining the Unimaginable: The Nature of Resilience**
Daniel Gottlieb, Ph.D
- 1:15p.m. Lunch and Exhibits**
- 2:15 p.m. Modern Perspectives on Neurologic Dysfunction in Friedreich's Ataxia**
David Lynch, M.D., Ph.D.
- 2:45 p.m. Advocacy and IEP**
Mark J. Bernstein, M.A
- 3:45p.m. Break and Exhibits**
- 4 p.m. Current Therapeutic Initiatives for Friedreich's Ataxia**
Robert B. Wilson, M.D., Ph.D.
- 4:30 p.m. Program Adjourns**

Reply Form

Friedreich's Ataxia Symposium - Saturday, December 6, 2008

Registration Deadline: November 21, 2008

Registrations will not be processed without form of payment. Faxed registration forms will be accepted for credit card payments only.

Registration Fee: \$50

Method of Payment (payable to The Children's Hospital of Philadelphia)

Personal Check Institutional Check

MasterCard American Express VISA Discover

Credit Card # _____

Exp. Date _____

Mail or fax the completed registration form with payment to:

Ms. Micah Holiday, Continuing Medical Education Department,
The Children's Hospital of Philadelphia, 34th Street and Civic
Center Boulevard, Philadelphia, Pa. 19104
215-590-5263 / Fax 215-590-4342 / holidaydm@email.chop.edu

Name _____

Home Address _____

City _____ State _____ Zip _____

Phone _____

Email _____

Organizing Committee

Felicia DeRosa, MPH

Program Manager

Friedreich's Ataxia Research Alliance

Jennifer M. Farmer, M.S., C.G.C

Coordinator, Collaborative Clinical Research Network in FA

Executive Director, Friedreich's Ataxia Research Alliance

Holly L. Hedrick, M.D.

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David Lynch, M.D., Ph.D.

Attending Physician, Division of Neurology

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Kim Schadt, R.N., B.S.N., C.C.R.P.

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Faculty

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John W. Bryfogle Professor of Medicine

Division of Cardiology

University of Pennsylvania School of Medicine

Robert B. Wilson, M.D., Ph.D.

Associate Professor of Pathology and

Laboratory Medicine

University of Pennsylvania School of Medicine

A Celebration of Spirit, Community and Hope Reception

Friday, December 5, 2008, 6:30 p.m.

Leonard and Madlyn Abramson Pediatric Research Center at The Children's Hospital of Philadelphia

The Reception will feature inspiring stories by Kyle Bryant, Chelsea Chamberlain and Samantha Bode, each who live life to the fullest with Friedreich's Ataxia.

FA Community Accomplishments and Artist Showcase

We are asking for individuals with FA to share a special piece of art, writing, or an accomplishment (photograph, etc...) with us for the reception. We will have display tables set-up to showcase achievements and artistic expressions of those with Friedreich's Ataxia as part of our celebration. This can be a past treasure or a recent accomplishment.

Invitations will be sent in early November, the reception is included in the conference registration fee.

To RSVP for the reception or submit an item for the showcase, please use the following web address:

[www.giftofchildhood.com/
celebrationofspiritcommunityandhope](http://www.giftofchildhood.com/celebrationofspiritcommunityandhope)



Friedreich's Ataxia Symposium

Saturday, December 6, 2008

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*(A Celebration of Spirit, Community
and Hope Reception)*



The Children's Hospital of Philadelphia

Hope lives here.

Continuing Medical Education Department

CH The Children's Hospital of Philadelphia®
Hope lives here.

34th Street and Civic Center Boulevard
Philadelphia, PA 19104-4399