




Third Annual Friedreich's Ataxia Symposium

Philadelphia Marriott Downtown
Philadelphia, PA

November 13, 2010

Sponsored by the Friedreich's Ataxia Program at

 The Children's Hospital of Philadelphia
Hope lives here.

Symposium 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.

Meeting Location

The symposium will be held Saturday, November 13, 2010 at the Philadelphia Marriott located in the heart of Center City. Just 20 minutes from the Philadelphia International Airport and within walking distances of exclusive shopping, world-class restaurants, art museums and historical sites.

Course Objectives

Upon completion of this activity, participants should be able to:

- Discuss developments in FA research
- Discuss current clinical approaches to care in FA
- Discuss continued research, clinical trials and scientific discovery
- Discuss the importance of advocacy
- Discuss the connection between disability and relationships

Registration Information

Pre-registration is required and the registration deadline is October 22, 2010. 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.

Registration fee includes course materials, continental breakfast, refreshments, lunch and entrance to the "Meet and Greet" on Friday evening, November 12, 2010.

"Meet and Greet"

Join us for an informal "meet and greet" on the evening of Friday, November 12, 2010 from 6 – 7:30p.m. in the Liberty Ballroom. Light refreshments will be provided. RSVP is required in advance; please check the box on the registration form.

Hotel Accommodations

A room block with reduced rates has been reserved at The Marriott. The group rates are \$149 single and double occupancy plus a 15.2% room tax. Participants are required to make their own hotel accommodations by calling the Marriott directly at 1-800-228-9290 or 215-625-2900. The special room rate will be available until Friday, October 22, 2010. After that date, reservations will be accepted on a space and rate availability basis. Please mention the group name "Friedreich's Ataxia - The Children's Hospital of Philadelphia" and use the reference #: M-1V11WH" when making your reservation.

Travel Scholarships

A limited number of travel scholarships will be offered to individuals who wish to attend the symposium and need financial assistance. For information on how to apply for a travel scholarship by the FA project, please contact Maria at maria@thefaproject.org. There are a limited number of scholarships available.

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, less a service charge, but is not responsible for any related costs, charges or expenses to participants, including cancellation charges assessed by airlines/travel agencies.

In order to process refunds for course withdrawals, cancellations must be received in writing by October 29, 2010. No refunds will be issued thereafter. Refunds will be issued for the amount of registration minus a \$40 service charge.

Services for the Disabled

Participation by all individuals is encouraged. If arrangements are required for an individual with special needs to attend this meeting, please contact the CME Department at (215) 590 - 5263 at least two weeks in advance so that we may provide better service to you during the conference.

Organizing Committee

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

*Attending Physician, Division of Neurology
The Children's Hospital of Philadelphia*

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

*Nurse Practitioner, Trisomy 21 Program and
Friedreich Ataxia Program
The Children's Hospital of Philadelphia*

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

*Coordinator, Collaborative Clinical Research Network in FA
Executive Director, Friedreich's Ataxia Research Alliance*

Holly Hedrick, M.D.

*Parent Consultant-Friedreich's Ataxia Program
The Children's Hospital of Philadelphia*

Conference Faculty

Richard Cohen

*Author and Journalists
Authority on Living with Chronic Illness*

Beth Kaufman, M.D.

*Interim Medical Director, Cardiomyopathy and Heart Failure Program
Interim Medical Director, Heart Transplantation Program
The Children's Hospital of Philadelphia
Assistant Professor of Pediatrics
University of Pennsylvania School of Medicine*

John H. Lockwood, CLU

*Financial Representative
Northwestern Mutual
Sacramento, CA*

R. Mark Payne, M.D., FACC

*Professor of Pediatrics (Cardiology)
Riley Hospital for Children
Wells Center for Pediatric Research
Indiana University School of Medicine*

Robbi A. Van Schoick, MPH

Independent Promoter of Friedreich's Ataxia Awareness

Steven M. Willi, M.D.

*Director, Diabetes Center for Children
Division of Endocrinology
The Children's Hospital of Philadelphia*

Everyday Hero

Your Everyday Heroes - Sharing Your Hero Stories

Who is your hero?
What did he or she do to win your admiration?
Maybe it was your hero's courage, outstanding achievements or noble qualities that touched you. Share your inspiration—tell us about your hero.

Submit a brief description (50 words or less) about your hero to:

FAProgram@email.chop.edu

Join us in celebrating everyday heroes whose selfless acts, courage and stories of bravery are sure to inspire.

November 13, 2010

7:30 a.m. Registration and Continental Breakfast

8 a.m. Welcome and Introduction
David R. Lynch, M.D., Ph.D.

8:15 a.m. Pathophysiology and Therapeutic Pathways
David R. Lynch, M.D., Ph.D.
Jennifer Farmer, M.S., C.G.C.
R. Mark Payne, M.D., FACC

9:15 a.m. Clinical Trial Update and Education
Jennifer Farmer, M.S., C.G.C.

9:45 a.m. The Heart in Friedreich's Ataxia: What Happens and Why Does it Matter?
M. Mark Payne, M.D., FACC

Advanced Cardiac Care Options in Friedreich's Ataxia
Beth Kauffman, M.D.

11 a.m. Break

11:15 a.m. Keynote Lecture
Strong at the Broken Places
Richard Cohen

12:30 p.m. Lunch, Book Signing

1:30 p.m. Neurology Update 2010
David R. Lynch, M.D., Ph.D.

2 p.m. Diabetes and Blood Sugar Abnormalities in Friedreich's Ataxia
Steven M. Willi, M.D.

**2:30 p.m. What Keeps You Up at Night Planning for a
Loved One with Special Needs?**
John H. Lockwood, CLU

3 p.m. Break

**3:30 p.m. Recognizing the Need for Specialized Healthcare Training:
The Personal Care Assistant (PCA) of a Care Recipient with Advanced
Friedreich's Ataxia**
Robbi A. Van Schoick, MPH

4:30 p.m. Symposium Adjourns

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The Friedreich's Ataxia Program • The Children's Hospital of Philadelphia

REGISTRATION FORM

Name(s) _____

Home Address _____

City _____ State _____ Zip _____

Country _____ Phone _____

Fax _____ Email _____

Conference Registration Fee: \$95 per person

- ☐ I will attend the Meet & Greet Reception on November 12th _____ # of people
- ☐ I am a wheelchair user
- ☐ I have a service dog
- ☐ Everyday Hero Submission (email to: FAProgram@email.chop.edu)

Method of Payment

- | | | |
|---|--|---|
| <input type="checkbox"/> Personal Check | <input type="checkbox"/> Institutional Check | <input type="checkbox"/> Discover |
| <input type="checkbox"/> MasterCard | <input type="checkbox"/> Visa | <input type="checkbox"/> American Express |

Credit Card # _____ Exp. Date _____

(Please make all checks payable to The Children's Hospital of Philadelphia. Registrations will not be processed unless accompanied by full payment. Faxed registrations will be accepted for credit card payment only.)

Mail/Fax the completed registration form and payment to:

Ms. Micah Holliday, Continuing Medical Education
The Children's Hospital of Philadelphia
34th Street and Civic Center Boulevard, Philadelphia, PA 19104
Phone/215-590-5263 Fax/ 215-590-4342 Email/ hollidaydm@email.chop.edu

For more information, please call
The Children's Hospital of Philadelphia
Continuing Medical Education Department
(215) 590 – 5263
www.chop.edu/cme



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