

# Second Annual Friedreich's Ataxia Symposium November 14, 2009

Philadelphia Marriott Downtown • Philadelphia, PA • USA

Sponsored by  
The Friedreich's Ataxia Program



The Children's Hospital of Philadelphia  
Hope lives here.



## Course Overview

Friedreich's Ataxia (FA) is a rare condition which leaves patients and families searching for more information and resources. 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

## 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

## "Meet and Greet" – November 13th

Join us for an informal "meet and greet" on the evening of Friday, November 13th from 6 to 7:30 pm in the Liberty Ballroom at the Philadelphia Marriott Downtown. Light refreshments, ballroom dance exhibition, artwork and networking.

## Registration Information

Pre-registration is required and the registration deadline is **November 9, 2009**. 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 13, 2009.

## Travel Scholarships

The FA Project is offering travel scholarships to individuals who would like to attend the symposium and need financial assistance. All individuals who would like to apply for these travel funds should contact **Maria Carrier** at [maria@theFAproject.org](mailto:maria@theFAproject.org). There are a limited number of scholarships available.

## Meeting Location

The conference will be held November 14, 2009 at the Philadelphia Marriott Downtown 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.

## 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 800-228-9290 or 215-625-2900. The special room rate will be available until Friday, October 16, 2009. 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 #: I-Y2520X" when making your reservation.**

- 7:30 a.m.            **Registration and Continental Breakfast**
- 8 a.m.                **Welcome and Introduction**
- 8:15 a.m.            **Positive Exposure: The Spirit of Difference**  
*Rick Guidotti*
- 9 a.m.                **Biochemical of Friedreich Ataxia**  
*Robert Wilson, M.D., Ph.D.*
- 9:30 a.m.            **Scoliosis in Friedreich's Ataxia**  
*John Flynn, M.D.*
- 10 a.m.               **Break and Exhibits**
- 10:30 a.m.           **Keynote Lecture**  
**Strong at the Broken Places**  
*Richard Cohen*
- Noon                  **Lunch, Exhibits, Book Signing by Richard Cohen**
- 1:30 p.m.            **Neurological Perspectives on Friedreich Ataxia**  
*David R. Lynch, M.D., Ph.D.*
- 2 p.m.                **Career Panel**  
*Richard Currier*  
*Keith Dalton*  
*Jennifer D'Antoni*  
*Allison Rice, B.S., CNMT*
- 3 p.m.                **Break and Exhibits**
- 3:30 p.m.            **Cardiac Issues with Friedreich Ataxia**  
*Robert Shaddy, M.D.*
- 4 p.m.                **Neuro Ophthalmological Issues in Friedreich Ataxia**  
*Laura Balcer, M.D., M.S.C.E.*
- 4:30 p.m.            **Pathways to Clinical Trials**  
*Jennifer M. Farmer, M.S., C.G.C.*
- 5 p.m.                **Rick Guidotti Encore**  
Photographs from the day
- 5:30 p.m.            **Adjourn**

## 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](http://www.pcvb.com) or [www.gophila.com](http://www.gophila.com)

## 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 November 11, 2009. 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.

*Trisomy 21 Program Coordinator  
Friedreich Ataxia Research Coordinator  
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

### Laura Balcer, M.D., M.S.C.E

*Chief, Multiple Sclerosis Division, Department of Neurology  
Hospital of the University of Pennsylvania  
Professor of Neurology, University of Pennsylvania School of Medicine*

### Richard Cohen

*Author and Journalist  
Authority on Living with Chronic Illness*

### Richard Carrier

*Accountant*

### Keith Dalton

*Elementary School Resource Room Teacher, Belleville School #5  
Belleville Board of Education*

### Jennifer D'Antoni

*Counselor/Advocate  
The New York Center for Interpersonal Development/NYCID*

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

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

### John M. Flynn, M.D.

*Associate Chief of Orthopaedic Surgery,  
The Children's Hospital of Philadelphia  
Associate Professor of Orthopaedic Surgery  
University of Pennsylvania School of Medicine*

### Rick Guidotti

*Photographer  
Positive Exposure*

### Allison Rice, B.S., CNMT

*Senior Clinical Research Coordinator  
Fletcher Allen Health Care*

### Robert Shaddy, M.D.

*Chief, Division of Cardiology, The Children's Hospital of Philadelphia  
Professor of Pediatrics, 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*

# Registration Form

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November 14, 2009  
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The Friedreich's Ataxia Program • The Children's Hospital of Philadelphia

Name(s) \_\_\_\_\_

Name(s) \_\_\_\_\_

Home Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Country \_\_\_\_\_ Phone \_\_\_\_\_

Fax \_\_\_\_\_ Email \_\_\_\_\_

**Conference Registration Fee: \$95 per person**

- I will attend the Meet & Greet on November 13th
- I am a wheelchair user
- I have a service dog

## Method of Payment

- Personal Check
- Institutional Check
- Discover
- MasterCard
- Visa
- 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

**[www.chop.edu/cme](http://www.chop.edu/cme)**