Symposium Overview

Friedreich's ataxia (FA) is a rare condition that leaves patients and families searching for more information and resources. While there is currently no cure for FA, efforts continue toward research that will one day halt or even reverse disease progression. The Friedreich’s Ataxia Center of Excellence 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 on therapeutic approaches and current research being conducted in the field of Friedreich’s ataxia.

Symposium 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

Meeting Location

The symposium will be held Monday, Oct. 17, 2016, at the Crowne Plaza Valley Forge in King of Prussia, Pa. The hotel is directly across from the King of Prussia Mall, the largest shopping mall in the United States, and is less than two miles from the Valley Forge National Historic Park, the site of Washington's troops’ winter encampment during the Revolutionary War.

Hotel Accommodations

A block of rooms with reduced rates has been reserved at the Crowne Plaza Valley Forge. The group rate is $129 single and double occupancy plus 8 percent room tax. Participants are required to make their own hotel reservations by calling the Crowne Plaza directly at 610-265-7500. The special room rate will be available until Tuesday, Sept. 13, 2016. After that date, reservations will be accepted on a space and rate availability basis. Please mention “Friedreich’s Ataxia – The Children’s Hospital of Philadelphia” when making your reservation.

Meet-and-Greet

Join us for an informal meet-and-greet on Sunday, Oct. 16 from 6 to 7:30 p.m. Light refreshments will be provided. **Your RSVP is required in advance; please check the box on the registration form.**

Poster Presentation

A special poster presentation will showcase current research, insights and innovative strategies in Friedreich's ataxia by young investigators, researchers and postdoctoral students. This will provide the opportunity for the research community to interact with patients and families while simultaneously allowing families to further engage the scientific community. An interactive poster session with the presenters will be featured on Sunday evening during the meet-and-greet reception. Posters can also be viewed during the lunch break on Monday.
Travel Scholarships
A limited number of travel scholarships will be offered to individuals who wish to attend the symposium and need financial assistance. For more information on how to apply for a travel scholarship from the FA Project, please contact Maria at maria@thefaproject.org. The FA Project is a nonprofit organization created to raise awareness and funds to benefit those affected by Friedreich’s ataxia. There is a limited number of scholarships available. The deadline to submit is Friday, Sept. 16, 2016.

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 Hospital will refund registration fees, less a $40 service fee, but is not responsible for any related costs, charges or expenses to participants, including cancellation charges assessed by airlines or travel agencies. In order to process refunds, cancellations must be received in writing by Monday, Oct. 3, 2016. No refunds will be issued thereafter.

Services for People with Disabilities
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. A two-week notice is preferred.

Everyday Hero
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!
7:30 a.m.  Registration and Continental Breakfast

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

8:05 a.m.  Sensory Dysfunction in Friedreich’s Ataxia
           David R. Lynch, M.D., Ph.D.

8:30 a.m.  Effects of Symptomatic Care in Friedreich’s Ataxia:
           Impact on Disease Evolution with Standardized Follow-up
           Isabelle Husson, M.D., Ph.D.

9:15 a.m.  Exercise in Friedreich’s Ataxia: Panel Discussion
           Kimberly Y. Lin, M.D.; Shana McCormack, M.D., M.T.R.; Bastien Roche, P.T.

10:15 a.m.  Break

10:30 a.m.  FARA Strategies and FA Treatment Pipeline
            Jennifer Farmer, M.S., C.G.C.

11 a.m.  Epigenetics of Friedreich’s Ataxia
         Sanjay I. Bidichandani, M.B.B.S., Ph.D.

Noon  Lunch

1:15 p.m.  Clinical Trials in Friedreich’s Ataxia: Current Status
           David R. Lynch, M.D., Ph.D.

2 p.m.  Metabolic Signaling in Heart as a Marker of Disease
        R. Mark Payne, M.D., F.A.A.P., F.A.C.C.

2:45 p.m.  Break

3:10 p.m.  Patient Panel: Exercise
           Moderator: Kyle Bryant

3:40 p.m.  Open Q&A — General Questions

4 p.m.  Adjourn
Symposium Faculty

Organizing Committee
Kyle Bryant
rideATAXIA
Founder/Program Director
FARA

Felicia DeRosa, M.P.A.
Program Director
FARA

Jennifer M. Farmer, M.S., C.G.C.
Coordinator
Collaborative Clinical Research Network in FA
Executive Director
Friedreich’s Ataxia Research Alliance (FARA)

Holly L. Hedrick, M.D., F.A.C.S.
Parent Consultant
Friedreich’s Ataxia Center of Excellence

Sanjay I. Bidichandani, M.B.B.S., Ph.D.
CMRI Claire Gordon Duncan Chair in Genetics
Professor of Pediatrics
University of Oklahoma College of Medicine
Oklahoma City, Okla.

Isabelle Husson, M.D., Ph.D.
Service de Neurologie Pédiatrique et des Maladies Métaboliques
INSERM U676
Hôpital Robert Debré – AP-HP
Paris, France

Kimberly Y. Lin, M.D.
Assistant Professor
Division of Cardiology
Penn-CHOP Friedreich’s Ataxia Center of Excellence, Cardiac Program Director

Shana McCormack, M.D., M.T.R.
Attending Physician
Division of Endocrinology and Diabetes
Asistant Professor of Pediatrics

R. Mark Payne, M.D., F.A.A.P., F.A.C.C.
Professor of Pediatrics (Cardiology)
Indiana University School of Medicine
Indianapolis, Ind.

Bastien Roche, P.T.
Physiotherapist in Child Neurology
Hôpital Robert Debré – AP-HP
Paris, France

Symposium Faculty

Unless otherwise noted, faculty is from The Children’s Hospital of Philadelphia and the Perelman School of Medicine at the University of Pennsylvania.
Registration – Friedreich’s Ataxia Symposium


*Name ____________________________________________________________________________

Home Address ______________________________________________________________________

City ____________________________________________ State _____ ZIP ____________________

Phone ____________________________________________________________________________

*Email ____________________________________________________________________________

(*Required field)

Conference Registration Fee: $95 per person (includes conference registration, materials, breakfast, lunch and breaks • maximum charge per family $285)

☐ I will attend the conference.

☐ Others attending conference: _______________________________________________________

(Please list all)

☐ I will attend the Meet-and-Greet Reception on Sunday, Oct. 16 with _________ additional people.

☐ I am a first-time conference attendee.

☐ I am a wheelchair user.  ☐ I have a service dog.

☐ I have a personal care assistant (PCA) attending with me. (Name: _____________________________)

☐ Everyday Hero submission (email to FApogram@email.chop.edu)

Method of Payment

Total $ ______________________

☐ Personal check   ☐ Institutional check

(Please make check payable to The Children’s Hospital of Philadelphia.)

☐ Discover   ☐ MasterCard   ☐ American Express   ☐ VISA

Credit Card # ______________________________________________________________________

Exp. Date ________________________________

Mail/fax the completed registration form and payment to:

Ms. Micah Holliday, Continuing Medical Education Department • The Children’s Hospital of Philadelphia • 3401 Civic Center Blvd. • Philadelphia, Pa. 19104-4399 • 215-590-5CME • Fax 215-590-4342 • hollidaydm@email.chop.edu

Photos/General Media:

I hereby irrevocably give The Children’s Hospital of Philadelphia perpetual authorization and permission to publish in any media, any and all video and photographs taken of me at the CHOP Friedreich’s Ataxia Symposium without any compensation due to me. I hereby waive any right that I may have to inspect and or approve the finished product and copy that may be used in conjunction therewith, or the use to which it may be applied.

Signature: ____________________________________________________________________________