

12th Annual Friedreich's Ataxia Symposium

Monday, Oct. 14, 2019

Crowne Plaza Valley Forge • King of Prussia, Pa.

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Donovan, 21, and Jack, 17



Symposium Information

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 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

Registration Fee

The registration fee is \$95 per person. This fee includes conference registration materials, breakfast, lunch, breaks and welcome reception. To register, please visit **chop.cloud-cme.com**.

Meeting Location

The symposium will be held Monday, Oct. 14, 2019, 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 \$132 for single and double occupancy plus 8% 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 Monday, Sept. 9, 2019. After that date, reservations will be accepted on a space and rate availability basis. Please mention the name of this conference when making your reservation.

Meet-and-Greet

Join us for an informal meet-and-greet on Sunday, Oct. 13, from 6 to 7:30 p.m. at the hotel. 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/Grants

A limited number of travel scholarships will be offered to first-time attendees only who wish to attend the symposium and need financial assistance.

FA Project

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. The deadline to submit is Monday, Sept. 16, 2019.

Race for Matt and Grace, Inc. (RFMG)

RFMG is an organization providing travel grants to the CHOP Friedreich's Ataxia Symposium for New England residents. For more information on how to apply, email michael.t.crawley.cpa@gmail.com no later than 5 p.m. EST on Monday, Sept. 30, 2019. Notification of grant award(s) will take place on or prior to Thursday, Oct. 10, 2019. Applicant shall be a New England resident who has been diagnosed with FA.

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 fewer) 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!

Cancellation and Refund Policy

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 Tuesday, Oct. 1, 2019. No refunds will be issued thereafter.

Program • Monday, Oct. 14, 2019

- 7:30 a.m. **Registration and Continental Breakfast**
- 7:55 a.m. **Welcome and Introduction**
David R. Lynch, MD, PhD
- 8 a.m. **New Insights in Epigenetic Silencing in FA**
Sanjay Bidichandani, MBBS, PhD
- 9 a.m. **Emerging Therapies in FA**
Jennifer Farmer, CGC
- 9:30 a.m. **Identifying New Approaches for Treatment in FA**
Robert Wilson, MD, PhD
- 10 a.m. **Clinical Management and Lessons from Clinical Studies in FA**
David R. Lynch, MD, PhD
- 10:30 a.m. **Break**
- 10:45 a.m. **Clinical Care and Research in FA-related Endocrine Disorders**
Shana McCormick, MD
- 11:15 a.m. **Vision in FA**
David R. Lynch, MD, PhD
- 11:45 a.m. **Q&A**
- 12:15 p.m. **Lunch**
- 1:30 p.m. **Flash Talks – Poster Presentations**
- 2 p.m. **Anxiety and Depression in the Context of Chronic Medical Illness**
Raghuram Prasad, MD
- 2:30 p.m. **Q&A**
- 2:45 p.m. **Break**
- 3 p.m. **Panel Discussion: Two Disabled Dudes Community Forum**
Live Recorded Podcast
Kyle Bryant
Sean Baumstark
- 3:30 p.m. **Open Q&A – General Questions**
- 4 p.m. **Adjourn**

Symposium Faculty

Unless otherwise noted, faculty is from Children's Hospital of Philadelphia and/or the Perelman School of Medicine at the University of Pennsylvania.

Organizing Committee

Kyle Bryant

rideATAXIA

Founder/Program Director

Friedreich's Ataxia Research Alliance

Felicia DeRosa, MPA

Program Director

Friedreich's Ataxia Research Alliance

Jennifer M. Farmer, MS, CGC

Coordinator

*Collaborative Clinical Research Network in FA
Executive Director*

Friedreich's Ataxia Research Alliance

Holly L. Hedrick, MD, FACS

Parent Consultant

Friedreich's Ataxia Center of Excellence

David R. Lynch, MD, PhD

*Co-director, Friedreich's Ataxia Center of
Excellence*

Attending Physician

Division of Neurology

Professor of Neurology

Kim Schadt, MSN, CRNP

Nurse Practitioner

Friedreich's Ataxia Center of Excellence

Symposium Faculty

Sam Baumstark

Patient Advocate

Sanjay I. Bidichandani, MBBS, PhD

CMRI Claire Gordon Duncan Chair in Genetics

Professor of Pediatrics

University of Oklahoma College of Medicine

Shana McCormack, MD, MTR

*Attending Physician, Division of Endocrinology
and Diabetes*

Assistant Professor of Pediatrics

Raghuram Prasad, MD

*Medical Director, Psychiatry for the Autism
Integrated Care Program*

Attending Physician and Psychiatrist

Assistant Professor of Clinical Psychiatry

Robert B. Wilson, MD, PhD

*Co-director, Friedreich's Ataxia Center of
Excellence*

*Senior Scientist, Center for Mitochondrial and
Epigenomic Medicine*

*Professor, Department of Pathology and
Laboratory Medicine*