

FA SYMPOSIUM AGENDA

OCTOBER 13, 2025

7:30 AM ● **Registration + Breakfast**

Freedom Foyer

7:30 AM ● **New to FA Community Breakfast**

Independence Ballroom

8:30 AM ● **Welcome**

Freedom Ballroom

Jen Farmer, Chief Executive Officer, FARA

8:45 AM ● **Managing FA Together: Clinical Insights for Patients and Families**

Freedom Ballroom

David Lynch, MD, PhD, Attending Physician, Division of Neurology, *The Children's Hospital of Philadelphia* & Director of the Friedreich's Ataxia Program, Professor of Neurology, and Co-Director, *FA Center of Excellence at Children's Hospital of Philadelphia (CHOP)*

Shana McCormack, MD, MTR, Associate Professor, Department of Pediatrics, Perelman School of Medicine, *University of Pennsylvania*, and Scientific Director, Neuroendocrine Center in the Division of Endocrinology and Diabetes, *The Children's Hospital of Philadelphia*

Kimberly Lin, MD, Associate Professor, Division of Cardiology and Medical Director, Pediatric Cardiomyopathy Program, *Perelman School of Medicine at the University of Pennsylvania* and *The Children's Hospital of Philadelphia*

9:45 AM ● **BREAK – MORNING REFRESHMENTS**

10:00 AM ● **Living Strong: FA Community Perspectives on Exercise and Sports**

Freedom Ballroom

Moderated by Kyle Bryant, rideATAXIA Director and Spokesperson, FARA

Jessie Beatty, Matt Lafleur, Jakob Mitterhauser, and Damon Vincent, CSCS, CPT

11:00 AM ● **Raise Your Voice With FARA: Advocate for FA Research!**

Freedom Ballroom

Brigid Brennan, Director of Advocacy, FARA

11:25 AM ● **Individuals with FA Group Photo**

Outside Front Entrance of Hotel

11:45 PM

Breakout Sessions – Choose One

1

FA & Speech Toolkit: Understanding Dysarthria and Tips To Be a More Confident Speaker

Freedom Ballroom

Caroline Spencer, PhD, Assistant Professor, Speech, Language and Hearing Sciences, *Indiana University*

Brigid Brennan, Director of Advocacy, *FARA*

Emma Potter, Advocacy Program Coordinator, *FARA*

LIVE STREAMED
for virtual participants

2

Mind Matters: Mental Wellness in Friedreich's Ataxia

Independence Ballroom

Jessica Hankinson, PhD, Hankinson Psychology

3

Parents and Caregivers: Connecting Through Experience and Learnings

Ground Floor Meeting Spaces

Moderated by Maureen Juip, Debra Simpson, and Norm Simpson

12:45 PM

LUNCH

1:45 PM

Keynote Session: The Light We Let In

Freedom Ballroom

Jeremy Cowart, Award-winning Photographer, Artist, and Entrepreneur

2:30 PM

FA Drug Development Pipeline Update and Q&A Panel

Freedom Ballroom

Moderated by Jennifer Farmer, Chief Executive Officer, *FARA*

Representatives from: Biogen, Design Therapeutics, Larimar Therapeutics, Lexeo Therapeutics, PTC Therapeutics, and Solid Biosciences

3:30 PM

BREAK

3:45 PM

New Science in FA

Freedom Ballroom

Typos in the GAA Expansion: Why it Matters

Sanjay Bidichandani, MBBS, PhD, Director Section Head of Genetics, *University of Oklahoma College of Medicine, Department of Pediatrics*

Exercise and NAD+ Precursor Supplementation in FRDA: Clinical Trial Results

Shana McCormack, MD, MTR, Associate Professor, Department of Pediatrics, Perelman School of Medicine, *University of Pennsylvania*, and Scientific Director, Neuroendocrine Center in the Division of Endocrinology and Diabetes, *The Children's Hospital of Philadelphia*

4:30 PM

Closing Remarks

Freedom Ballroom

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