

FARA/UCLA

Friedreich's Ataxia Patient Symposium

FRIDAY - FEBRUARY 21, 2020



- 8:30 - 9:30am: **Registration and Continental Breakfast** - Catalina Ballroom/Foyer
- 9:30 - 10:00am: **Welcome**
- Overview of FA, Clinical Care Recommendations**
Susan Perlman, MD, Director of Clinical Trials, Neurology Program, UCLA, and Investigator, FA Collaborative Clinical Research Network
- 10:00 - 10:30am: **Molecular Mechanisms and Avenues of Therapeutic Intervention in FA**
Elisabetta Soragni, PhD, Associate Director of Research, FARA
- 10:30 - 10:45am: **Break**
- 10:45 - 11:45am: **Clinical Trials & Biopharma Panel**
Moderator: Jen Farmer, MS, Chief Executive Officer, FARA
Panelists: Peter Milner MD, FACC, CMO Retrotope, Inc.,
Kara Fick, Associate Director, Patient Advocacy, Reata Pharmaceuticals
Mark Payne, MD, CSO & Co-Founder Chondrial Therapeutics
- 11:45 - 12:15pm: **Turning the Frataxin Gene on with Synthetic Transcription Factors**
Sean Jeffries, PhD, Design Therapeutics
- 12:15 - 1:15pm: **Lunch**
- 1:15 - 1:45pm: **Gene Therapy, The Key Questions: What, How, Why and When?**
Susan Walther, MS, CGC, Director of Patient Engagement, FARA

2:00 - 2:45 pm: **Breakout Session 1:**

Cardiac Symptom Management – Catalina Ballroom

Moderator: Mark Payne, MD, Pediatric Cardiology, Indiana School of Medicine, Advisor, FARA Scientific Advisory Board

Ways to be Involved – Los Angeles and Irvine Meeting Room

Moderators: Susan Walther, MS, CGC, Director of Patient Engagement, FARA Felicia DeRosa, MPA, Vice President Fundraising & Communications, FARA

Living with FA: Connecting with Each Other – Berkeley and Anaheim Meeting Room

Moderators: Paul Konanz, Patient Advocate, Moderator of FAPG Kyle Bryant, rideATAXIA Founder & Director, FARA

2:45 - 3:00pm: **Break – Transition to Second Breakout Session**

3:00 - 3:45pm: **Breakout Session 2:**

Cardiac Symptom Management – Catalina Ballroom

Moderator: Mark Payne, MD, Pediatric Cardiology, Indiana School of Medicine, Advisor, FARA Scientific Advisory Board

Ways to be Involved – Los Angeles and Irvine Meeting Room

Moderators: Susan Walther, MS, CGC, Director of Patient Engagement, FARA Felicia DeRosa, MPA, Vice President Fundraising & Communications, FARA

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4:00 - 4:30pm: **Closing Remarks and Q&A – Catalina Ballroom**

----- Meeting End -----

NOTE: Please join us after the meeting, between 4:30 and 6:00 pm, to visit with friends and pick-up your rideATAXIA SoCal participant packet! For more information or to register for rideATAXIA SoCal, please visit rideATAXIA.org/socal.