



MOVING FORWARD TOGETHER

Family & Scientific Conference Preliminary Agenda



MAY 25 SATURDAY

- 2:00 - 7:00 pm Registration for All Attendees
- 5:00 - 7:00 pm Community Connections and Posters!
- 5:00 - 7:00 pm Welcome Reception

MAY 26 SUNDAY

- 7:30 - 9:00 am Breakfast and Conference Check-In
- 9:00 - 10:00 am Conference Kickoff with The GFPD Board of Directors
- 10:00 - 11:15 am Peroxisomal Disorders: A Multiple System Rare Disease
- 11:15 - 11:30 am Health Literacy Resources for Real Life
- 12:00 - 1:00 pm Lunch
- 1:30 - 2:30 pm Remembrance Ceremony
- 1:30 - 2:30 pm Breakout: Adults with Peroxisomal Disorders
- 3:00 - 4:00 pm Day in the Life: Deafblind Simulation
- 3:00 - 4:00 pm Medical and Scientific Session
- 3:00 - 4:00 pm Breakout: Bereavement Support
- 4:15 - 5:00 pm Breakout: Parents of Adults with Peroxisomal Disorders
- 4:30 - 5:30 pm Breakout: Extended Family
- 5:30 - 6:00 pm Community Connections and Posters!
- 6:00 - 8:00 pm Welcome, Opening Dinner, and Research Updates

MAY 27 MONDAY MEMORIAL DAY

- 6:30 - 8:30 am Labs
- 7:30 - 9:00 am Breakfast
- 8:45 - 9:00 am Morning Welcome
- 9:00 - 9:15 am GFPD Patient Registry for Peroxisomal Disorders
- 9:15 - 9:45 am Home Care: A Discussion on Decisions and Services
- 10:00 - 11:30 am Professional Pop-ins | Now Includes Meetings with Medical and Scientific Advisors
- 10:30 - 11:00 am Breakout: Extended Family
- 11:00 - 12:00 pm Breakout: Bereavement Support
- 12:00 - 1:00 pm Lunch
- 1:00 - 4:00 pm Professional Pop-ins | Now Includes Meetings with Medical and Scientific Advisors
- 5:30 - 8:30 pm Island Dinner and Dance
- 6:30 - 6:45 pm Breaking Down Barriers

MAY 28 TUESDAY

- 7:00 - 9:00 am Breakfast and Externally-Led Patient-Focused Drug Development (EL-PFDD) Meeting Check-In
Detailed EL-PFDD Meeting Agenda Coming Soon
- 8:30 - 9:00 am Morning Welcome
- 9:00am - 12:00 pm EL-PFDD Meeting: Symptoms and Impacts
- 12:00 - 1:00 pm Lunch
- 1:30 - 4:15 pm EL-PFDD Meeting: Clinical Trials and Outcomes
- 5:00 - 6:00 pm GFPD Board and Medical and Scientific Advisor Meeting
- 5:30 - 7:00 pm Grab and Go (or stay!) Dinner
- 7:00 - 8:30 pm Parent Night

MAY 29 WEDNESDAY

- 7:30 - 9:00 am Breakfast
- 9:00 - 10:00 am Peroxisomes and People: Research Updates!
- 9:30 - 11:00 am Breakout: Bereavement Support
- 10:00 - 11:15 am Medical and Scientific Advisors Panel
- 11:15 - 11:30 am Empowering your Providers with TeleEcho
- 12:00 - 1:00 pm Lunch
- 1:30 - 2:30 pm Warriors in Action: Getting Involved in Advocacy Fundraising, and Awareness
- 1:30 - 3:00 pm Medical and Scientific Session
- 2:30 - 2:45 pm Engaging with the GFPD on Social Media
- 2:30 - 3:30 pm Breakout: Extended Family
- 2:45 - 3:15 pm Diversity Equity and Inclusion for GFPD Warriors
- 3:15 - 4:00 pm Your Clinical Elevator Pitch
- 3:30 - 4:30 pm Moving Forward Together
- 5:30 - 7:30 pm GFPD Family Farewell Dinner

Agenda subject to change.



GLOBAL
FOUNDATION
• for •
PEROXISOMAL
DISORDERS