



pfic | Advocacy & Resource
Network, Inc.

Family & Scientific Conference 2023

May 4-6, 2023 | Orlando, Florida

Conference Agenda & Details

Thursday, May 4 | Room: Lantana

- 3:00 PM Patient/Family Volunteer Rally
- 5:00 PM Conference Check In & Poster Session
- 7:00 PM Welcome Reception & Icebreaker Activity - Room Lantana

Friday, May 5 | Room: Monterrey 1

- 8:00-8:15 AM **Welcome Address**

- 8:15-8:45 AM **Keynote Address: Patient Centered Outcomes Research**
Dr. Jim Squires, Children's Hospital of Pittsburgh
Paired with: Alex Perez, Parent, Canada

- 8:45-9:15 AM **PFIC Network Science & Research Program: Updates on the Registry, Grant Proposals, and the Science Blog + Q&A (virtual)**
Dr. Gitta Lubke, PFIC Network

- 9:15-10:00 AM **Clinical Care for PFIC: What does "disease progression" mean, and how do you measure it? + Q&A**
Dr. Benjamin Shneider, Texas Children's Hospital
Paired with: Rachael Turek, Parent, USA

- 10:00-10:45 AM **Liver Transplant in PFIC + Q&A**
Dr. Greg Tiao, Cincinnati Children's Medical Center
Paired with: Brittany Brinson, Parent, USA

- 10:45-11:15 AM **Short Break - 30 Minutes**

- 11:15-12:00 PM **Therapeutic Development 101: What it takes to develop a new therapy + Q&A**
Part 1: From concept through clinical trials (15 minutes) Presented by: Lara Longpre, Mirum Pharmaceuticals
Part 2: Submitting for regulatory approval and commercializing (15 minutes) Presented by: Lauren Wilkinson, Albireo Pharmaceuticals
Paired with: Cadence Crompton, Patient, Canada

- 12:00-12:45 PM **Taking Research from Bench-to-Bedside: Chaperones and PFIC + Q&A (virtual)**
Dr. Thomas Falguières & Dr. Emmanuel Gonzales, Université Paris- Saclay
Paired with: Laura Susoi, Parent, Canada

- 12:45-1:30PM **Lunch Break - 45 minutes** - Conference Room/Patio
Presentations resume after 45 minutes, but buffet will be available until 2 pm. **(Continues on Back)**

- 1:30-2:15 PM **The psychosocial impact of living with a rare chronic disease on youth and their families + Q&A**
Caitlin Shneider M.A., Doctoral Candidate, Georgia State University
Paired with: Cedar Ventura, Patient, USA
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- 2:15-3:00 PM **Updates from ChiLDReN + Q&A**
Dr. Paula Hertel, Texas Children's Hospital
Paired with: Rocio Cavazos, Parent, Mexico
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- 3:00-3:45 PM **Updates from the NAPPED Consortium + Q&A**
Antonia Felzen, MD/PhD candidate, University of Groningen, Netherlands
Paired with: Tara Kearns, Parent, USA
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- 3:45-4:30 PM **What's with the Number? PFIC Subtypes and the Meaning of a Genetic Diagnosis**
Dr. Richard Thompson, Kings College London
Paired with: Brittany Brinson, Parent, USA
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- 4:30-4:45 PM **Short Break - 15 Minutes**
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- 4:45-5:30 PM **Full Panel Roundtable**
All presenters, Open Q&A with discussion
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- 5:30-5:45 PM **Conference Debrief Activity (Closed Session for Patients and Families)**
Facilitated by: Lisa Jensen
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- 6:00-8:00 PM **Networking Reception & Dinner at Disney Coronado's Villa Del Lago**

Saturday, May 6 | Room: Yucatan 1

- 8:00-9:00 AM **Science Engagement Focus Group (Closed)**
- 9:20-10:20 AM **PFIC Network Patient Registry Focus Group (Closed)**

Extra Details

- Check in begins at 5 PM on Thursday, May 4. PFIC Network staff and volunteers will be set up in the Lantana Conference room at this time.
- Breakfast will **not** be served in the conference room. All attendees will receive a \$25 gift card to cover breakfast options for Friday morning. Gift cards can be used at any Disney location. If you did not receive a gift card at check-in, please find one of our staff members.
- If you would like to volunteer to help with setup or any tasks that may be needed during the conference, please email lisa@pfic.org.
- Friday night dinner is at Villa Del Lago in the center of the Coronado Springs Campus.
- If you have any questions at any time before, during, or after the conference, please email info@pfic.org.