

PFIC Family Conference-2 Day Lounge Line Up All times in London BST (UTC+1)

Conference Main Lounge Friday, July 16

14:00-14:15 Welcome & Introduction to PFIC Network *Presented by: Walter Perez, Tara Kearns, Emily Ventura*

14:15-15:15 Keynote Speech #1: Basics of Genetics, Introduction to PFIC as a set of Genetic Disease of Cholestasis

Presented by: Dr. William Balistreri, MD, Dr. Chunyue Yin, PhD

15:30-16:30 What's in the Research

- Introduction to research in PFIC, what barriers exist Presented by Dr. Henkjan Verkade, MD
- NAPPED Study
 Presented by Dr. Henkjan Verkade, MD
- What is known: Pruritus Presented by Dr. Binita Kamath, MD
- The PFIC Patient Registry in partnership with CoRDS Presented by Professor Gita Lubke & Alyssa Mendel

16:40-17:40 Scientific Discussions: Drug Development related to PFIC

- Update on IBAT Inhibitors: BylvayTM (odevixibat) and Ensuring Patient Access to PFIC Therapy Presented by: Christine Clemson, M.S.C.I., PhD. & Pamela Stephenson, Albireo Pharma
- Update on ASBT Inhibitors: Maralixibat Presented by: Pamela Vig, PhD, Mirum Pharmaceuticals
- Discussions about Gene Therapy Presented by: Pamela Vig, PhD, Mirum Pharmaceuticals

18:00-19:00 What is PFIC? For young patients (school age & teens)

Presented by: Dr. James Squires, MD

19:00-19:30 Peer Support & Engagement: Kids take over the lounge

- Show & Tell / Arts & Crafts / Meet & Greet!

20:00-21:00 Pruritus & Nutrition in PFIC: "Back to the Basics"

Presented by: Dr. Ben Schneider

23:00-overnight *Lounge will stay open to replay recordings of earlier sessions

Global Ambassador Lounge Friday, July 16

12:00-14:00

.. UK ..

16:30-18:30

.. Netherlands

19:00-21:00

.. Germany ..

21:00-23:00

.. Canada ..

Conference Main Lounge Saturday, July 17

14:00-15:00 Considerations related to COVID & PFIC

Presented by: Dr. Ron Sokol

15:10-16:20 Ambassador Training, North America, South America, Eastern Europe

- Émily Ventura, PFIC Network
- Swapna Kakani, Everylife Foundation
- Francesca Lombardozzi, PFIC Italia Network
- Bernadetta Skora, PFIC Network Polska
- Dania Nair & Andrew Scott, Global Liver Institute
- Michelle Wilkins, Children's Liver Disease Foundation
- Sindee Weinbaum, European Liver Patient Association

16:30-17:30 Keynote Speaker #2: Genetics of PFIC by Subtype

Presented by: Dr. Richard Thompson, Dr. Laura Bull

18:00-19:00 Mental Health and Daily Life Concerns

Presented by: TBA

19:15-20:15 Q&A Present Panel Discussion

Panelistss: Dr. Ben Schneider, Dr. Richard Thompson, Dr. Laura Bull, Dr. Henkjan Verkade, Dr. James Squires, Dr. Alexander Miethke, Dr. Chunyue Yin, Dr. William Balistreri

20:30-21:30 Peer Support and Patient Engagement

Presented by: Parent/patient advisory board

21:30-22:00 Peer Support and Engagement

Patients and Caregivers Networking in Lounge

22:00-23:00 Motivation, Inspiration, Closing Remarks

23:00-overnight *Lounge will stay open to replay recordings of earlier sessions

Global Ambassador Lounge Saturday, July 17

11:00-13:00

.. India ..

14:00-16:00

.. Pakistan ..

17:30-19:30

.. Italy ..

19:30-21:30

.. Poland ..

23:30-01:30

.. Australia