



**PFIC Family Conference-2 Day Lounge Line Up**  
**All times in Rome CEST (UTC+2)**

Conference Main Lounge Friday, July 16	Global Ambassador Lounge Friday, July 16
<p><b>15:00-15:15</b> Welcome &amp; Introduction to PFIC Network  <i>Presented by: Walter Perez, Tara Kearns, Emily Ventura</i></p> <p><b>15:15-16:15</b> <b>Keynote Speech #1: Basics of Genetics, Introduction to PFIC as a set of Genetic Disease of Cholestasis</b>  <i>Presented by: Dr. William Balistreri, MD, Dr. Chunyue Yin, PhD</i></p> <p><b>16:30-17:30</b> <b>What's in the Research</b></p> <ul style="list-style-type: none"> <li>- Introduction to research in PFIC, what barriers exist <i>Presented by Dr. Henkjan Verkade, MD</i></li> <li>- NAPPED Study <i>Presented by Dr. Henkjan Verkade, MD</i></li> <li>- What is known: Pruritus <i>Presented by Dr. Binitha Kamath, MD</i></li> <li>- The PFIC Patient Registry in partnership with CoRDS <i>Presented by Professor Gita Lubke &amp; Alyssa Mendel</i></li> </ul> <p><b>17:40-18:40</b> <b>Scientific Discussions: Drug Development related to PFIC</b></p> <ul style="list-style-type: none"> <li>- Update on IBAT Inhibitors: Bylvay™ (odevixibat) and Ensuring Patient Access to PFIC Therapy <i>Presented by: Christine Clemson, M.S.C.I., PhD. &amp; Pamela Stephenson, Albireo Pharma</i></li> <li>- Update on ASBT Inhibitors: Maralixibat <i>Presented by: Pamela Vig, PhD, Mirum Pharmaceuticals</i></li> <li>- Discussions about Gene Therapy <i>Presented by: Pamela Vig, PhD, Mirum Pharmaceuticals</i></li> </ul> <p><b>19:00-20:00</b> <b>What is PFIC? For young patients (school age &amp; teens)</b>  <i>Presented by: Dr. James Squires, MD</i></p> <p><b>20:00-20:30</b> <b>Peer Support &amp; Engagement: Kids take over the lounge</b></p> <ul style="list-style-type: none"> <li>- Show &amp; Tell / Arts &amp; Crafts / Meet &amp; Greet!</li> </ul> <p><b>21:00-22:00</b> <b>Pruritus &amp; Nutrition in PFIC: "Back to the Basics"</b>  <i>Presented by: Dr. Ben Schneider</i></p> <p><b>00:00-until next day starts</b> *Lounge will stay open to replay recordings of earlier sessions</p>	<p><b>16:00-18:00</b></p> <p>..</p> <p>..</p> <p>UK</p> <p>..</p> <p>..</p> <p><b>17:30-19:30</b></p> <p>..</p> <p>..</p> <p>Netherlands</p> <p>..</p> <p>..</p> <p><b>20:00-22:00</b></p> <p>..</p> <p>..</p> <p>Germany</p> <p>..</p> <p>..</p> <p><b>22:00-00:00</b></p> <p>..</p> <p>..</p> <p>Canada</p> <p>..</p> <p>..</p>

Conference Main Lounge  
Saturday, July 17

**15:00-16:00 Considerations related to COVID & PFIC**

*Presented by: Dr. Ron Sokol*

**16:10-17:20 Ambassador Training**

- Emily 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

**17:30-18:30 Keynote Speaker #2: Genetics of PFIC by Subtype**

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

**19:00-20:00 Mental Health and Daily Life Concerns**

*Presented by: TBA*

**20:15-21:15 Q&A Present Panel Discussion**

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

**21:30-22:30 Peer Support and Patient Engagement**

*Presented by: Parent/patient advisory board*

**22:30-23:00 Peer Support and Engagement**

Patients and Caregivers Networking in Lounge

**23:00-00:00 Inspiration, Motivation & Closing Remarks**

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

Global Ambassador Lounge  
Saturday, July 17

**12:00-14:00**

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India  
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**14:00-16:00**

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Pakistan  
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**18:30-20:30**

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Italy  
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**20:30-22:30**

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Poland  
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**20:30-03:30**

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Australia  
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