



## **Congenital Hyperinsulinism Family Conference**

**Renaissance Wien Hotel - Vienna, Austria**

**September 20-22, PM**

Sponsored by:

Kongenitaler Hyperinsulinismus e.V., Lobby4Kids and Congenital Hyperinsulinism International

**Friday, September 20, 2019**

**18.00 – 20.00**      **HI Family and Medical Professional Welcome Reception**

**Saturday, September 21, 2019**

**8.30**      **Registration**

**9.00–9.45**      **Welcome, Statement of Goals, and HI Advocacy**

*Ulrike Seyfarth, Kongenitaler Hyperinsulinismus e.V., Irene Promussas, Lobby4Kids, and Julie Raskin, Congenital Hyperinsulinism International*

**9.45-10.45**

**HIStories** - Family Presentations on Life with HI - *HI Family Members; Danielle Drachmann and others TBD, moderated by Ulrike Seyfarth*

**10.45-11.15**

**Networking Break** – And Group Photo

**11.15-11.45**

**The HI Global Registry – The Inaugural Year Report** - *Davelyn Hood, MD, MBA, Congenital Hyperinsulinism International*

**11.45–12.45**

**HI Family Listening Session** - *Ask the Family Experts, moderated by Julie Raskin* **12:45–**

**13.00**

**Recent Research and International Work from Alder Hey** - *Senthil Senniappan, MD, PhD*

**13.00-14.00**

**Networking Lunch**

**14.00-14.45**

**Psychological Burden of Living with Hyperinsulinism** - *Caroline Culen, PhD*

**14.45-15.30**

**Feeding Issues** - *Senthil Senniappan, MD, PhD, Isabel Calderon and GOSH Nurses, moderated by Isabel Calderón*

And **Workshop for Young Adults** - *Christa Egger, Paul Seyfarth and Stella Promussas*

- 15.30-16.00**            **Networking Break**
- 16.00–16.45**            **Managing HI at School** - *Christa Egger, Cristina Pindado, and GOSH Nurses, moderated by Irene Promussas*
- 16.45–17.30**            **Transition from Pediatric to Adult Care** - *Caroline Culen, PhD, Stella Promussas, GOSH Nurses*  
**Parallel:**                **Relaxation techniques for Adults,** *Klaus Bierbaumer*
- 18.00-19.00**            **Reception – Refreshments and Appetizers**
- 19.00-21.00**            **Dinner and Entertainment**

**Sunday, September 22, 2019**

- 8.30-8.45**            **Welcome and Registration**
- 8.45-9.00**            **Why Participate in Clinical Research?** - *Davelyn Hood, MD, MBA*
- 9.00-9.20**            **Guidelines for Detecting Hypoglycemia** - with a discussion about what the patient community can do to support adopting guidelines worldwide, *Paul Thornton, MD with Julie Raskin*
- 9.20-9.40**            **Congenital Hyperinsulinism Explained** - *Thomas Meissner, MD*
- 9.40-10.10**            **The Genetics of Hyperinsulinism** - Why we need a genetic report and how to read it - *Sarah Flanagan, PhD*
- 10.10-10:30**            **Imaging in the Diagnosis of Congenital Hyperinsulinism** - *Oliver Blankenstein, MD*
- 10.30-11.00**            **Networking Break**
- 11.00-11.45**            **Current Treatments for Congenital Hyperinsulinism** - *Pratik Shah, MD, PhD, Louise Conwell, MBBS (Hons), PhD, and Winfried Barthlen, MD, Diva De León, MD*
- 11.45 -12.15**            **Long-term Outcomes in Congenital Hyperinsulinism** – *Diva De León, MD, Klaus Mohnike, MD*
- 12.15-13.15**            **Recent International Research and Investigative Projects**
- *Oliver Blankenstein, MD*
  - *Louise Conwell, MBBS(Hons), PhD*
  - *Diva De León, MD*
  - *Sarah Flanagan, PhD*
  - *Thomas Meissner, MD*
  - *Klaus Mohnike, MD*
  - *Pratik Shah, MD, PhD*
  - *Paul Thornton, MD*
- 13.15-14.15**            **Lunch**
- 14.15-15.00**            **Recent Biotech International Research and Investigative Project**
- Rezolute
  - Zealand
  - Xeris
  - NovoNordisk

**15.00-15.45**

**Ask the Experts – Facebook Live**

- *Oliver Blankenstein, MD*
- *Diva De León, MD*
- *Louise Conwell, MBBS(Hons), PhD*
- *Sarah Flanagan, PhD*
- *Thomas Meissner, MD*
- *Klaus Mohnike, MD*
- *Pratik Shah, MD, PhD*
- *Paul Thornton, MD*
- *Rezolute, Zealand, Xeris*

End of Conference