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**Congenital Hyperinsulinism Family Conference**

**September 16-18, 2022**

**Hotel NH Roma Villa Carpegna**

**Via Pio IV 6**

**Rome, Italy**

**Friday, September 16, 2022**

**18.00 – 21.00**  **Meet and Greet -** Dinner Reception

**Saturday, September 17, 2022**

**8.30**  **Registration and Networking**

**9.30**  **Opening Remarks**

*Paola Giuliani, Daniela Forcella, Julie Raskin, and Jennifer Schmitt (Conference Organizers)*

**9.40**  **"Dare to Dream: A Vision for a Future without Lows"**

*Presenter: Charles Stanley, MD, Children’s Hospital of Philadelphia*

**10.10**  **Congenital Hyperinsulinism (HI) in Italy**

Diagnosis and Treatment

*Presenter: Arianna Maiorana, MD, Bambino Gesu’ Hospital in Rome*

**10.40 Networking Break**

**11.10** **Presenting the HI Global Registry and the CHI Collaborative Research Network**

*Patient-driven global initiatives*

*Presenters: Julie Raskin, Congenital Hyperinsulinism International, Ulrike Seyfarth, Kongenitaler Hyperinsulinismus e.V., Cristina Pindado, AFHICO*

**11.40**  **Learning about the Genetic Causes of HI and** **Understanding your Genetic Report**

*Presenter: Sarah Flanagan (virtual), PhD, Molecular Genetics Laboratory, University of Exeter*

**12.10**  **Glucose Monitoring in Congenital Hyperinsulinism:**

* + - * Do HI patients benefit from using CGMs?
      * How are CGMs used in scientific studies?

*Presenters: Antonia Dastamani, MD, Great Ormond Street Hospital, Indi Banerjee, MD, Royal Manchester Children’s Hospital*

**12.40** **Management of HI After Diagnosis and Treatment Regimen has been Established:**

* + - * When is a Change in Management needed to Reduce Hypoglycemia?
      * When can Medical Treatment/Carbohydrate Therapy be Stopped?
      * When is a Change in Management Needed to Reduce Hyperglycemia?

*Presenter: Diva De León-Crutchlow, MD, Children’s Hospital of Philadelphia*

**13.10**  **Lunch**

**14.10**  **Feeding and Eating:**

* Should diet play a role in managing congenital hyperinsulinism by HI type? If so, how?
* What are strategies to help with feeding issues?

*Presenters: Thomas Meissner, MD, University Children’s Hospital Düsseldorf, Sara Osimani, MD, San Raffaele Scientific Institute*

**14:40 Biotechs on the Move**: **Treatments in Development (part 1)**

* *Rezolute: Davelyn Hood, MD and Jeffrey Breit, PhD*
* *Crinetics: Christine Ferrara-Cook, MD, PhD*

**15.10 Networking Break**

**15.40 Biotechs on the Move**: **Treatments in Development (part 2)**

* *Eiger BioPharmaceuticals: Colleen Craig, MD*
* *Hanmi: Hyungjin Cho, MD*
* *Zealand Pharma: Jelena Ivkovic, MD and Chandra Slusser*

**16.20 Hyperinsulinism 101: Ask the Experts**

*Chair and Moderator of Session: Giuseppe Chiumello, MD, Faculty of Medicine, University of Milan*

**Sample Question Topics:**

Challenges to Managing HI in infants and Toddlers

HI and Growth and Development

Feeding difficulties

Nutrition

When Hypoglycemia is Still an Issue

Transition from Pediatric to Adult Care

More on Genetics

Dealing with Highs and Lows

Issues with Access to Care

Rare Disease Advocacy

Devices

Sick Days

HI Global Registry

Participating in Research Studies

*Speakers:*

*Indi Banerjee, MD, Royal Manchester Children’s Hospital*

*Oliver Blankenstein, MD, Charite Hospital*

*Laura Byers, Great Ormond Street Hospital*

*Henrik Christesen, MD, Hans Christian Anderson Children’s Hospital*

*Diva De León-Crutchlow, MD, Children’s Hospital of Philadelphia*

*Hüseyin Demirbilek, MD, Hacettepe University*

*Maria Salomon Estebanez, MD, Royal Manchester Children’s Hospital*

*Sebastian Kummer, MD, University Children’s Hospital Düsseldorf*

*Katherine Lord, MD, Children’s Hospital of Philadelphia*

*Arianna Maiorana, MD, Bambino Gesu’ Hospital in Rome*

*Thomas Meissner, MD, University Children’s Hospital Düsseldorf*

*Roberta Pajno, MD, Milan Ospedale San Raffaele Scientific Institute*

*Charles Stanley, MD, Children’s Hospital of Philadelphia*

*Chris Worth, MD, Royal Manchester Children’s Hospital*

*And Biotech Speakers*

*16.50* **Congenital Hyperinsulinism In Turkey**

*Presenter: Hüseyin Demirbilek, MD, Hacettepe University*

**17.05 End of daytime programming**

**18.00 – 21.00 Conference Reception and dinner with**

**Keynote Speaker: A Parent on a Mission: Meet Claudine van der Sande, CEO of Xinvento**

**Sunday, September 18, 2022**

**9.00** **The Role of Advocacy in** **Advancing Compassionate Care for Children with HI**

*Presenter:* *Sir Albert Aynsley-Green, MD*

*With guided discussion*

**9.45**  **Living with HI – Our stories**

**Vivere Con CHI presentation followed by presentations from Families in Italy**

*Presented and moderated by**Daniela Forcella and Paola Guiliani*

Other presenters:*Patient, caregivers, and advocates share their experiences and work*

**10.45 Networking Break**

**11.00**  **Coping with the Stress of Parenting a Child with Congenital Hyperinsulinism**

*Presenter: Julie Raskin*

**11:15 Small Group Discussions on Special Topics**

* Newly Diagnosed – *Moderated by Arianna Maiorana* – no translator
* Families of Teens with Hyperinsulinism/Young Adults *– Moderated by Charles Stanley, MD and Paul Seyfarth*
* Hyperinsulinism at School- *Moderated by TBD*
* Open Discussion *Moderated* - *Ulrike Seyfarth and Oliver Blankenstein*, MD

**12.00 Optional Networking Lunch**