



**Congenital Hyperinsulinism Family Conference**

**Hilton Liverpool City Centre**

3 Thomas Steers Way

Liverpool, UK

**November 14-16, 2024**

**Organized by:**

**Congenital Hyperinsulinism International with the Children's Hyperinsulinism Charity**

**Thursday, November 14, 2023**

**6:00 PM – 8:00 PM**     **HI Family and Medical Professional Welcome Reception  
Buffet Dinner and Drinks**

**Friday, November 15, 2024**

**8:00 AM - 8:45 AM**     **Registration  
Babysitting Registration and drop-off**

**8:45 AM – 8:55 AM**     **Welcome**  
Julie Raskin, Congenital Hyperinsulinism International (CHI),  
Sarah Dearman, Children's Hyperinsulinism Charity (CHC)

**8.55 AM - 9.25 AM**     **"Learning from the Past and Planning for the Future"**  
Discussion with Sir Al Aynsley Green, MD and Charles Stanley, MD  
Moderated by Clare Gilbert, Clinical Nurse Specialist and Trudy Ward, MSC, Queens Nurse and  
CHI Board of Trustee Member

**9:25 AM – 9:45 AM**     **Learning about the Genetic Causes of HI and New Novel Approaches to Uncovering the  
Genetic Cause of Congenital Hyperinsulinism**  
Presenter: Sarah Flanagan, PhD

**9.45 AM – 10:15 AM**     **Current and Future Medical Treatments**  
Presenters: Antonia Dastamani, MD and Senthil Senniappan, MD

**10:15 AM - 10:35 AM**     **Networking Break**

**10:35 AM– 11:15 AM**     **HIStories - Family Presentations on Life with HI**  
Presenters: Teenagers and Young Adults with HI  
Moderated by Amanda Orr

<b>11:15 AM -12:00 PM</b>	<p><b>UK Specific Initiatives:</b></p> <p><b>Children’s Hyperinsulinism Charity Work</b>      Ciara Grace</p> <p><b>British Care Guidelines</b>                              Indi Banerjee, MD</p> <p><b>Congenital Hyperinsulinism BPSU Project</b>      Helen Couch, MD</p>
<b>12:00 – 12:40 PM</b>	<p><b>The 2024 CHI Centers of Excellence: Why This Designation Program Matters</b></p> <p><b>CHI</b> – Kristen Rohli, PhD</p> <p><b>NORCHI</b> – Indi Banerjee, MD, and Senthil Senniappan, MD</p> <p><b>GOSH</b> - Antonia Dastamani, MD</p> <p><b>CHOP</b> - Diva De León-Crutchlow, MD</p> <p><b>Charite</b> - Peter Kuhnen, MD and Oliver Blankenstein, MD</p> <p><b>Düsseldorf</b> –Sebastian Kummer, MD</p> <p><b>COACH</b> - Klaus Mohnike and Susann Empting, MD</p> <p><b>Odense University Hospital</b> – Henrik Christesen, MD, PhD</p>
<b>12:40 PM – 1:40 PM</b>	<b>Lunch</b>
<b>1:40 PM – 2:00 PM</b>	<b>An interview with Scott Bennett, HI Dad and Comedian</b>
<b>2:00 PM – 2:20 PM</b>	<p><b>Patient-Powered Research – The HI Global Registry</b></p> <p><b>An Interactive Discussion and Learning Session</b></p> <p>Presenter: Lauren Lopez, PhD</p>
<b>2:20 PM – 2:55 PM</b>	<p><b>The Collaborative Research Network</b></p> <p><b>Sharing progress: Universal Newborn Screening, Glucose as a Vital Sign, Access initiatives, and CGM Use in HI Community. Panel Discussion with Program Leaders</b></p> <p>Moderated by Tai Pasquini</p> <p>With Julie Raskin, Al Aynsley-Green, MD, Diva D. De León-Crutchlow, MD, Sarah Flanagan, PhD, Clare Gilbert, Nurse Practitioner, Kate Morgan, Clinical Nurse Specialist, Jennifer Schmitt, Helen Couch, MD, and Chris Worth, MD</p>
<b>2:55 PM – 3:30 PM</b>	<p><b>Learning about Clinical Research from People in the Biotechnology Field</b></p> <p>A moderated discussion</p> <p>Moderated by Julie Raskin</p> <p>Speakers are members of the Biotechnology Community</p>
<b>3:30 PM – 4:15 PM</b>	<p><b>Ask the Experts</b></p> <p><b>Congenital Hyperinsulinism Experts Assembled to Respond to Participants Questions:</b></p> <p>Moderated by Senthil Senniappan, MD</p> <p><b>Possible Question Topics:</b></p> <p>Challenges to Managing HI in infants and Toddlers</p> <p>HI and Growth and Development</p> <p>When Hypoglycemia is Still an Issue</p> <p>More on Genetics</p> <p>Dealing with Highs and Lows</p> <p>Transition from Pediatric to Adult Care</p> <p>Issues with Access to Care</p> <p>Rare Disease Advocacy</p> <p>Devices</p> <p>Sick Days</p>

## Research Projects

### Panelists:

Sir Albert Aynsley-Green, MD, Emeritus, University College London  
Indi Banerjee, MD, Royal Manchester Children's Hospital  
Oliver Blankenstein, MD, Charite Hospital  
Henrik Christesen, MD, PhD, Odense University Hospital  
Antonia Dastamani, MD, Great Ormond Street Hospital  
Diva De León-Crutchlow, MD, Children's Hospital of Philadelphia  
Sarah Flanagan, PhD, University of Exeter  
Clare Gilbert, Clinical Nurse Specialist, Great Ormond Street Hospital  
Martin Gotthardt, Professor, Radboud University Medical Center  
Sebastian Kummer, MD, University Children's Hospital Düsseldorf  
Peter Kühnen, MD, Charite Hospital  
Kate Morgan, Clinical Nurse Specialist Great Ormond Street Hospital  
Senthil Senniappan, MD, Alder Hey Hospital  
Pratik Shah, MD, PhD, Barts Health and Queen Mary University  
Charles Stanley, MD, Children's Hospital of Philadelphia  
Chris Worth, MD, Royal Manchester Children's Hospital

**4:15 PM -5:00 PM      Small Group Discussions**

### **Breakout Groups by Special Topics for HI Family Members and Clinicians**

- How to Manage and Overcome Feeding Issues
- HI Nutrition
- Managing HI at School
- Coping with Stress
- Living with HI as a Teenager
- Living with HI as an Adult
- Special Needs and HI
- Grandparents Group
- Dad's Group
- Genetics Discussion Group
- Hybrid Breakout Group - Managing HI in Developing Countries: A real challenge for families and physicians. Led by led by Sommaya Aftab, MD:

**6:30 – 9:00 PM      Dinner Reception**

**Saturday, November 16, 2024**

**8:15 AM      Babysitting Registration and drop-off**

**9:00 AM – 9:45 AM      HIStories - Family Presentations on Life with HI**  
Moderated by Steff Bradley

**9:45 AM – 10:00 AM      The LightCure Project**  
Martin Gotthardt, MD

**10:00 AM – 10.40 AM      Breakout groups by HI subtype**

- Diazoxide-Responsive Diffuse
- Diffuse Non-Diazoxide Responsive
- HI/HA

- Focal
- Diabetes secondary to HI
- Cured

**10:40 AM – 11:00 AM    Networking Break**

**11:00 AM -11:45 AM    Quality of Life Session**

**Your Voice has Power: How Research Helps to Tell the HI Story**

Presenter: Tai Pasquini, PhD

**LightCure Quality of Life Study**

Presenter: Stefanie Witt, PhD

**Q & A about HIGR/LightCure/Sharing what are the most pressing quality of life issues**

Moderator: Tai Pasquini, PhD

**11:45 AM – 12:00 PM    Conference Highlights Recap**

Julie Raskin and Sarah Dearman

**12:00 PM – 1:00 PM    Lunch**

**Close of Conference**