



Congenital Hyperinsulinism Family Conference Philadelphia, PA, April 14-16

Friday, April 14, 2023
Sheraton Philadelphia University City Hotel
3549 Chestnut Street
Philadelphia, PA 19104

6:00 PM – 8:30 PM Meet and Greet – Dinner Reception

Saturday, April 15, 2023
Leonard and Madlyn Abramson Pediatric Research Center
Children's Hospital of Philadelphia
3615 Civic Center Blvd
Philadelphia, PA 19104

8:00 AM Registration and Continental Breakfast

9:00 AM Opening Remarks
Diva D. De León-Crutchlow, MD, MSCE and Julie Raskin, MA

9:10 AM Understanding the Role of Insulin in the Human Body
Show-Ling Shyng, PhD

9:25 AM Diagnosing HI

- **Genetic and Unknown and Acquired Causes of HI**
Jennifer Kalish, MD, PhD and Vicki Sanders, MS, LCGC
- **Guidelines for Detecting and Managing Neonatal Hypoglycemia**
Paul Thornton, MD in conversation with a leading neonatologist

10:00 AM ***Surgery and HI***

- **Radiologic Tools**
Lisa States, MD
- **Surgical Update in the Treatment of HI**
N. Scott Adzick, MD, MMM, FAAP, FACS

10:25 AM Networking Break

10:45 AM ***Managing and Treating HI***

- **Current Medical Treatment Options**
Diva D. De León-Crutchlow, MD, MSCE
- **Glucose Monitoring for HI**
Antonia Dastamani, MD
- **Safety Fasts and Cure Fasts**
Winnie Sigal, MD, Linda Boyajian, CRNP

11:20 PM **HI-Stories: Sharing Triumphs and Challenges**
Moderator: Lora Van Arsdell, PsyD (Alex and Tara Latanzo, Felicia and Jilani Huffman, Marie-Claire Archbold, and more tbd)

12:10 PM **Networking Lunch and Poster Session**

1:10 PM **Hyperinsulinism Research**

- **CHI Collaborative Research Network**
Julie Raskin, MA
- **Dare to Dream**
Charles Stanley, MD
- **Natural History**
Elizabeth Rosenfeld, MD, Tai Pasquini, PhD, Indi Banerjee, MD
- **CGM Use for People with HI**
Chris Worth, MD, PhD
- **The Quest for the “Unknown” Causes of HI**
Diva D. De Leon, MD, MSCE
- **Stem Cell Modeling**
Timo Otonkoski, MD, PhD

2:10 PM **Panel Discussion**
Challenges and Opportunities in Rare Pediatric Disease Research
Paul Thornton, MD in conversation with specialists

2:40 PM **Clinical HI Research Biotech**

- Rezolute Bio
- Crinetics
- Hanmi
- Eiger BioPharmaceuticals
- Zealand Pharma

3:30 PM **Networking Break**

3:45 PM **Ask the Specialists** (Your chance to ask leading experts anything! whatever you want to know about hyperinsulinism)

Possible Question Topics:

- Transition from Pediatric to Adult Care
- Challenges to Managing HI in infants and Toddlers
- HI and Growth and Development
- When Hypoglycemia is Still an Issue
- Dealing with Highs and Lows
- Issues with Access to Care
- Rare Disease Advocacy
- Devices
- Sick Days
- HI Global Registry
- More on Genetics

Moderators: Julie Raskin, MA and Lora Van Arsdell, PsyD
Panelists:

- *Charles Stanley, MD*
- *Diva D. De León-Crutchlow, MD, MSCE*
- *Klaus Mohnike, MD*
- *Paul Thornton, MD*
- *Indi Banerjee, MD*
- *Elizabeth Rosenthal, MD, PhD*
- *Linda Boyajian, CRNP*
- *Katherine Lord, MD*
- *Winnie Sigal, MD*

- *Nicole Stewart, RN*
- *Jennifer Kalish, MD, PhD*
- *Sarah Barnes, RN, CDE*
- *Heather McKnight-Menci, CNRP*
- *Sherri Cohen, MD, MPH, FAAP*
- *Leela Morrow, PhD*
- *Liesje N. Carney, CSP, LDN, Diet and Nutrition*
- *Vicki Sanders, MS, LCGC*
- *Tai Pasquini, PhD*
- *Lisa States, MD*
- *Chris Worth, MD, PhD*
- *Timo Otonkoski, MD, PhD*
- *Show-Ling Shyng, PhD*
- *Clare Gilbert, Nurse Specialist*
- *Kate Morgan, Nurse Specialist*
- *Presenters from Biotech*

- 4:15 PM** **HI Songs with Janna Pelle and the CHIbras!**
- 4:30 PM** **Adjourn from CHOP for the day**
- 6:00 PM** **Reception and CHI Family Dinner at the Sheraton Philadelphia University City Hotel**
- 7:30 PM** **Dance Party with Janna Pelle and Eric Vanderzee**

Sunday, April 16, 2023
Leonard and Madlyn Abramson Pediatric Research Center
Children's Hospital of Philadelphia
3615 Civic Center Blvd
Philadelphia, PA 19104

- 8:00 AM** **Continental Breakfast**
- 9:00 AM** **HI Jeopardy**
Leaders: Heather McKnight, CRNP, Clare Gilbert, Nurse Specialist, Kate Morgan, Nurse Specialist
- 9:20 AM** **HI and Child Development**
Sophie Foss, PhD, Katherine Lord, MD, Klaus Mohnike, MD
- 9:50 AM** **The Psychosocial Impact of Living with HI**
Presenter: Leela Morrow, PhD
- 10:20 AM** **Concurrent Session I: Learning More about Different Types of HI**
- A. Focal HI Forum**
B. GDH-HI
C. HI and Diabetes
D. Diffuse, Non-diazoxide Responsive Still Hypoglycemic HI
E. Diazoxide Responsive Non-GDH-HI
F. Syndromic HI (BWS, Turner, Kabuki, Sotos)
- 11:00 AM** **Networking Break**
- 11:20 AM** **HI Issues Related to Feeding, Eating, Nutrition, GI**
Sherri Cohen, MD, Asim Maqbool, MD
- 12:00 PM** **Living with HI in the World and How to Manage it: Daycare, School, Work**
Jury Vera, RN, BSN, CC

12:30 PM **What's New in the World of Devices**
Kelli O'Connell MS, RD, LDN, CDCES, CPT

1:00 PM **Conference Wrap-Up**

1:15 PM **Reunion Lunch**
Sharing Milestones and Challenges

- Newly Diagnosed
- Toddlers
- School aged kids
- Teenagers
- Young adults
- Adults