



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

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, Julie Raskin, MA

9:05 AM Understanding the Role of Insulin in the Human Body

Show-Ling Shyng, PhD

9:20 AM Diagnosing HI

- **Genetic and Unknown and Acquired Causes of HI**

Jennifer Kalish, MD, PhD, Vicki Sanders, MS, LCGC

- **Guidelines for Detecting and Managing Neonatal Hypoglycemia: Pediatric Endocrinology and Neonatology Perspectives.**

Paul Thornton, MD, Jeff Kaiser, MD

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 (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 in 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 **HI Global Registry**
Compiling Shared Experiences to Better Diagnose and Treat HI
Tai Pasquini, PhD, Mahi Mesfin

2:30 PM **Clinical HI Research: Unmet Need**
Julie Sheldon, JD in conversation with Julie Raskin, MA

2:40 PM **What is Clinical Research and What do I Need to Know about Participating?**
Tai Pasquini, PhD

2:50 PM **Conversation with Biotech Representatives**
Moderated by Julie Raskin, MA

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

3:30 PM **Networking Break**

3:45 **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
More on Genetics
Dealing with Highs and Lows
Issues with Access to Care

Rare Disease Advocacy
Devices
Sick Days
HI Global Registry
Moderators: 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 Rosenfeld, MD, PhD*
- *Linda Boyajian, CRNP*
- *Katherine Lord, MD*
- *Winnie Sigal, MD*
- *Nicole Stewart, RN*
- *Jennifer Kalish, MD, PhD*
- *Sarah Barnes, RN, CDE*
- *Heather McKnight, CNRP*
- *Sherri Cohen, MD, MPH, FAAP*
- *Leela Morrow, PsyD*
- *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*

- 4:25 PM** **HI Songs with Janna Pelle and the CHIbras!**
- 4:40 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, PsyD
- 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
Sherrri Cohen, MD, Asim Maqbool, MD, Liesje N. Carney, CSP, LDN

12:00 PM A Discussion about Living with HI in the World and How to Manage it: Daycare, School, Work
Jury Vera RN, BSN, CCE, Lora Van Arsdell, PsyD, Others tbd

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 Reunion Lunch
Sharing Milestones and Challenges

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

2:15 HIGR Drop In
Pop in and ask any questions about HIGR – how to register, how to update, accessing MaxHIGR, or just say hello!
CHI Staff