



## 2017 Congenital Hyperinsulinism Family Conference

July 15-16, 2017  
Stockton Seaview Hotel  
Galloway, NJ

Saturday

- 8:00 a.m. Registration and Continental Breakfast**
- 8:30 a.m. Opening Remarks**  
Diva De León, MD, Children's Hospital of Philadelphia (CHOP)  
Julie Raskin, Congenital Hyperinsulinism International (CHI)
- 8:40 a.m. What is HI?**  
Understanding the Role of Insulin in the Human Body  
Understanding the Underlying Causes of Hyperinsulinism/The Genetics of Hyperinsulinism  
**Presenters:** Diva De León, MD, Paul Thornton, MD, Cook Children's
- 9:10 a.m. Understanding your Genetic Report**  
How to Read your Report and what it Means When the Genetic Report is Negative  
**Presenter:** Jessica Ebrahimzadeh, MS, University of Pennsylvania
- 9:40 a.m. When HI is Co-morbid with Other Conditions (BWS, Turners, Kabuki)**  
**Presenter:** Jennifer Kalish, MD, CHOP
- 10:10 a.m. Review of Current Treatment Options**  
Diazoxide  
Octreotide  
Lanreotide  
Enteral Feeds  
Surgery and Pet Scan  
**Presenters:** Diva De León, MD, Lisa States, MD, CHOP
- 10:50 a.m. Morning Break**
- 11:10 a.m. Industry Reports on Investigational Medications and HI Endocrinology Research Updates**

**Presenters:** CHOP, Paul Thornton, MD, Indi Banerjee, MD, University of Manchester, Klaus Mohnike, MD, University of Magdeburg, Pratik Shah, GOSH, Daniel Moller, Zealand, XOMA,

**12:10 p.m. Coping with Blood Sugar Fluctuations at Home**

Dealing with Low Blood Sugars – What to do and When a Change in Management is Necessary

Sick Days

When Exercise or Normal Daily Routines are Interrupted

**Presenter:** Heather McKnight-Menci and Linda Boyajian

**12:30 p.m. Lunch**

**1:30 p.m. Developmental and Medical Outcomes**

**Presenters:** Amanda Bennett, MD, CHOP, Katherine Lord, MD, Asim Macqbool, MD (GI Issues), CHOP, Klaus Mohnike, MD

**2:20 p.m. Coping with Stress of Parenting a Child with Chronic Health Issues**

**Presenter:** Julie Gettings, PhD, CHOP

**3:00 p.m. Break**

**3:20 p.m. Break-Out Groups**

-Diffuse – Non-Diazoxide Responsive -- Klaus Mohnike, MD

-Focal and/or Cured -- Pratik Shah, MD

-Diazoxide-Responsive non HIHA – Linda Boyajian, NP, CHOP, Katherine Lord, MD

-HIHA (GDH) - Diva De León, MD, Indi Banerjee, MD

-Management of Diabetes Secondary to Congenital Hyperinsulinism - Paul Thornton, MD, Heather McKnight-Mensi

**4:10 p.m. Speed Dating with the Specialists**

- Strategies for Handling Bullying – Julie Gettings, PhD, CHOP

- A Closer Look at your Genetic Report, Jessica Ebrahimzadeh, MS

- Navigating Insurance Issues—Nicole Stewart, BSN, CHOP

- New Technologies in the Management of Diabetes with a Focus on Diabetes for those born with HI Post-pancreatectomy-- Steven Russell, MD, PhD, Massachusetts General, Heather McKnight-Mensi, CNRP, CHOP

- A closer look at HI and Developmental Issues -- Amanda Bennett, MD

- Update on Devices, TBD

- Pediatric Endocrinology Open Question Time with all available speakers - Diva De León, MD, Paul Thornton, MD, Katherine Lord, MD, Indi Banerjee, MD, Klaus Mohnike, MD, Pratik Shah, GOSH

**5:00 p.m. Free Time**

**6:15 p.m.      Family Dinner**

**Sunday**

**8:00 a.m.      Continental Breakfast**

**8:30 a.m.      HIsTories: Congenital Hyperinsulinism Families, Children, and Teenagers Share their Experiences**

**Presenters:** CHI Family Participants

**9:30 a.m.      Feeding Issues, Nutrition**

**Presenters:** Sherri Cohen, MD, CHOP, Sarah Barnes, MS, CHOP

**10:15 a.m.      Break**

**10:35 a.m.      Discussion on Managing Congenital Hyperinsulinism at School**

**Presenter:** Kathleen Wegener, Special Education Teacher and HI Parent

**11:15 a.m.      CHI in Action: HI Global Registry, Research, Family Support, and Awareness**

**Presenters:**

Davelyn Hood, MD, CHI

Julie Raskin

**12:00 p.m.      Wrap-up and Conference Adjournment**