

2017 CONGENITAL HYPERINSULINISM FAMILY CONFERENCE

JULY 15 – 16, 2017

Stockton Seaview Hotel • Galloway, N. J.



SATURDAY, JULY 15

8 a.m. **Registration and Continental Breakfast**

8:30 a.m. **Opening Remarks**

Diva De León, MD, MSCE, *Children's Hospital of Philadelphia (CHOP)*

Julie Raskin, MA, *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 Positive or Negative

Presenter: Jessica Ebrahimzadeh, MS, *CHOP*

9:40 a.m. **When HI Is Comorbid with Other Conditions (BWS, Turners, Kabuki)**

Presenter: Jennifer Kalish, MD, PhD, *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. **Break**

11:10 a.m. **Industry Reports on Investigational Medications and HI Endocrinology Research Updates**

Presenters: Diva De León, MD, MSCE; Amanda Ackermann, MD, PhD, *CHOP*; Paul Thornton, MD;

Indi Banerjee, MD, *Royal Manchester Children's Hospital*; Klaus Mohnike, MD, *Magdeburg Hospital*;

Pratik Shah, MD, *Great Ormond Street Hospital*

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 and When Exercise or Normal Daily Routines Are Interrupted

Presenters: Heather McKnight-Menci, MSN, BSN, BA, CRNP, *CHOP*, and Linda Boyajian, MSN, CRNP, *CHOP*

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

- 1:30 p.m. **Developmental and Medical Outcomes**
Presenters: Amanda Bennett, MD, MPH, *CHOP*; Katherine Lord, MD, *CHOP*; Asim Macqbool, MD, *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 p.m. **Break**
- 3:20 p.m. **Break-out Groups**
- Diffuse/Non-diazoxide Responsive – Klaus Mohnike, MD; Katherine Lord, MD
 - Focal and/or Cured – Pratik Shah, MD
 - Diazoxide-responsive Non-HIHA – Linda Boyajian, MSN, CRNP; Amanda Ackermann, MD, PhD
 - HIHA (GDH) – Diva De León, MD, MSCE; Indi Banerjee, MD
 - Management of Diabetes Secondary to Congenital Hyperinsulinism – Paul Thornton, MD; Heather McKnight-Menci, MSN, BSN, BA, CRNP; Steven Russell, MD, PhD
- 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-Menci, MSN, BSN, BA, CRNP
 - A Closer Look at HI and Developmental Issues – Amanda Bennett, MD, MPH
 - 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, MD
- 5 p.m. **Free Time**
- 6:15 p.m. **Family Dinner**

SUNDAY, JULY 16

- 8 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, MPH, *CHOP*; Sarah Barnes, MS, RD, CSP, LDN, *CHOP*
- 10:15 a.m. **Break**
- 10:35 a.m. **Discussion on Managing Congenital Hyperinsulinism at School**
Presenter: Kathleen Wegener, MS, 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, *Family Medicine, San Antonio, Texas*; Julie Raskin, MA
- Noon **Wrap-up and Conference Adjournment**