



2018 Congenital Hyperinsulinism Family Conference

July 27-29, 2018

Hilton Garden Inn Fort Worth Medical Center
Fort Worth, TX

Friday, July 27

7:00 p.m. Meet and Greet

Saturday, July 28

8:00 a.m. Registration and Continental Breakfast

8:30 a.m. Opening Remarks

Paul Thornton, MD, *Cook Children's, Fort Worth, TX*

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

Presenter: Charles Stanley, MD, *Children's Hospital of Philadelphia (CHOP)*,

8:55 a.m. Understanding your Genetic Report

Presenter: Klaus Brusgaard, PhD, *Odense University Hospital, Odense, Denmark*

9:10 a.m. Review of Current Treatment Options

- Diazoxide
- Octreotide
- Lanreotide
- Enteral Feeds
- Surgery and Pet Scan

Presenters: Paul Thornton, MD, Jonathan Nedrelow, MD, John Uffman, MD, Irene Castaneda-Sanchez, MD

Cook Children's

9:50 a.m. Young Adults and Teenagers Share their Experiences

David Maher and Ashlee Tallis

10:20 a.m. Morning Break

10:40 a.m. The Neonatal Journey
Jonathan NedreLOW, MD, *Cook Children's*

**11:10 a.m. Developmental and Medical Outcomes
(Research Studies and Who to Screen, What to Screen for, and When to Screen [and
how to recognize there is a need for screening]?)**
Presenters: Diva D. De León MD, *CHOP*, Cortney Wolfe, PhD *Cook Children's*

11:40 Industry/Academic Speed Reports on Investigational Medications and Studies
Rezolute, Crinetics, Zealand, CHOP, Cook Children's, Otto von Guericke University,
Great Ormond Street, London, England, (GOSH), Odense University Hospital

12:30 p.m. Lunch

1:30 p.m. Break-Out Groups

- **Coping with Stress of Parenting a Child with Chronic Health Issues**
Dana Shafir, PhD, *Cook Children's*, Ryan Murphy, LCSW, *Cook Children's*
- **Nutrition, Diet, Exercise**
Katie Kennedy, MS, RD, LD, CDE, *Cook Children's*, Kathy O'Bryan, MS, RD, LD, *Cook Children's*
- **Coping with Blood Sugar Fluctuations at Home**
Dealing with Low Blood Sugars – What to do and When a Change in Management is
Necessary, Paul Thornton, MD, *Cook Children's*
How to Manage HI During Sick Days
Lisa Truong, CPNP, *Cook Children's*, Lauren Steinkamp, RN, *Cook Children's*
- **Coping with Feeding Issues**
Pratik Shah, MD, *GOSH*

2:30 p.m. Coffee Break

2:50 p.m. Break-Out Groups

- **Focal and/or Cured**
Charles Stanley, MD, *CHOP*
- **Diazoxide-Responsive non HIHA**
Klaus Mohnike, MD, Lisa Truong, CPNP, *Cook Children's*
- **HIHA (GDH)**
Pratik Shah, MD, *GOSH*
- **Management of Diabetes Secondary to Congenital Hyperinsulinism**
Diva De León, MD, *CHOP*
- **Non-diazoxide or Partially Diazoxide Responsive and Still Hypoglycemic (with
or without surgery)**
Paul Thornton, MD, *CHOP*

3:35 pm

Speed Dating with the Specialists (With Posters) and Exhibit Hall

- Adjusting to New Normals
Dana Shafir, PhD, *Cook Children's*
- A Closer Look at your Genetic Report
Klaus Brusgaard, PhD, *Odense University Hospital, Odense*
- Navigating Insurance Issues
Ryan Murphy, LCSW, *Cook Children's*
- New Technologies in the Management of Diabetes with a Focus on Diabetes for those born with HI Post-pancreatectomy
Diva De León, MD, *CHOP*
- A closer look at HI and Developmental Issues
Klaus Mohnike, MD, *Otto von Guericke University*
- Update on Devices, Paul Thornton, MD, *Cook Children's*
- HI Global Registry, Davelyn Hood, MD, *CHI*
- Open Question Time with Specialists
Paul Thornton, MD, *Cook Children's*; Diva De León, MD, *CHOP*; Klaus Mohnike, MD, *Otto von Guericke University*; Pratik Shah, MD, *GOSH*; Charles Stanley, MD, *CHOP*, Lisa Truong, *Cook Children's*, CPNP
- Meet Cook Children's Therapy Dog!
Kat Davitt and Chanel (Dog), *Cook Children's*

5:00 p.m. Free Time

6:15 p.m. Family Dinner

Sunday, July 29

8:00 a.m. Continental Breakfast

8:30 a.m. Histories: Congenital Hyperinsulinism Families Share their Experiences
Presenters: CHI Family Participants

9:30 a.m. Prevalence Studies
Presenters: Paul Thornton, MD, *Cook Children's*, Klaus Mohnike, MD, *Otto von Guericke University*, Klaus Brusgaard, PhD, *Odense University Hospital*

10:00 a.m. Yoga
Presenter: Cortney Reynolds, PhD, *Cook Children's*

10:35 a.m. Discussion on Managing Congenital Hyperinsulinism at School
Presenter: Dina Tallis EDD, *Director of Elementary Education and Support Services, Imlay Public Schools, and HI Parent*

11:15 a.m. CHI in Action: HI Global Registry, Research, Family Support, and Awareness
Presenters: Davelyn Hood, MD, MBA, *CHI* and Julie Raskin, *CHI*

12:15 p.m. Wrap-up and Conference Adjournment