



Congenital Hyperinsulinism Family Conference
The Hague Marriott Hotel
Johan de Wittlaan 30, The Hague, Netherlands 2517 JR

September 22-24, 2023

Organized by:
Congenital Hyperinsulinism International with the Netherlands Parent Support Group and Kongenitaler Hyperinsulinismus e.V.

Friday, September 22, 2023

18.00 – 20.00 **HI Family and Medical Professional Welcome Reception**

Saturday, September 23, 2023

8.30 **Registration**

9.00–9.15

Welcome

Presenters: Julie Raskin, Congenital Hyperinsulinism International, Maureen van Nooijen-Bakker and Ulrike Seyfarth, Kongenitaler hyperinsulinismus e.V

9:15-9:45

"Dare to Dream: A Vision for a Future without Lows"

Presenter: Charles Stanley, MD, Children's Hospital of Philadelphia

9.45-10.30

HISTories - Family Presentations on Life with HI

Presenters: HI Family Members and Young Adults with HI

10.30-11.00

Networking Break – And Group Photo

11.00-11.45

Hyperinsulinism Global Advocacy - Patient-driven global initiatives

**CHI International, the HI Global Registry and the CHI Collaborative Research Network
Kongenitaler hyperinsulinismus e.V,**

Presenters: Tai Pasquini, Indi Banerjee, MD, NORCHI, Julie Raskin, Ulrike Seyfarth, Janet Lee

11.45 – 12.45

The Role of Advocacy in Advancing Compassionate Care for Children with HI

Presenter: Sir Albert Aynsley-Green, MD

With guided discussion to better understand the need for compassion across the milestones of the HI experience.

12.45-13.45

Networking Lunch

13.45-14.15

**Congenital Hyperinsulinism (HI) in the Netherlands
A Conversation**

Diagnosis, Treatment, and Advocacy

Mirjam van Albada, University of Groningen

The Road to a Patient Organization in the Netherlands

Hajo Wildschut, HI Grandfather and Obstetrician

- 14:05-14:35** **Current and Future Medical Treatments**
Presenters: Diva De León-Crutchlow, MD, Children’s Hospital of Philadelphia
Paul Thornton, MD, Cook Children’s
- 14.35 – 15.05** **Learning about Clinical Trials from People in the Biotechnology Field**
 Crinetics, Eiger, Hanmi, Rezolute, Zealand
- 15.05– 16.00** **Ask the Experts**
Congenital Hyperinsulinism Experts Assembled to Respond to Participants Questions:

Possible Question Topics:

- 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
- Transition from Pediatric to Adult Care
- Issues with Access to Care
- Rare Disease Advocacy
- Devices
- Sick Days
- HI Global Registry

16.00 – 17.00 **Small Group Discussions**

- Learning disabilities, physical disabilities, and developmental differences
- Feeding issues
- Diabetes
- How HI affects relationships – Friends and Family
- Dealing with continued hypoglycemia
- Dealing with fear of hypoglycemia

18.00-19.00 **Reception – Refreshments and Appetizers**

19.00-21.00 **Dinner and Entertainment**

Sunday, September 24, 2023

8.30-9.00 **Welcome and Registration**

9.00-9.15 **Second Day Reflections: What Interesting Thoughts and Questions do Participants Have to Share?**

- 9:15-10.00** **Feeding and Eating Presentation and Discussion:**
- Should diet play a role in managing congenital hyperinsulinism by HI type? If so, how?
 - What are strategies to help with feeding issues?
- Presenter: Thomas Meissner, MD, University Children’s Hospital Düsseldorf*

10.00-10.45 **Quality of Life Research and Discussion**

Overview of Research on Quality of life from Düsseldorf and CHI

Presenter: *Marcia Roeper, MD, Tai Pasquini, PhD*

10.45-11.15

Networking Break

11.15-12.00

Small Group Discussions – What are the quality of life issues with HI at each stage of life?

By Age and Phase of Life

Baby/Toddler

School Aged

Teens

Adults

Grandparents

12.00

Conference Adjourns

13.00

HI Global Registry Workshop – Optional