

2023 CONGENITAL HYPERINSULINISM FAMILY CONFERENCE IN THE HAGUE

September 22 -24, 2023

The Hague Marriott

Johan de Wittlan 30, The Hague



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
Buffet Dinner and Drinks – Room A1 Foyer – Ground Floor**

Saturday, September 23, 2023

All sessions will take place in Room A1 on the Ground Floor

8.00 **Registration - Room A1 Foyer
Babysitting Registration and drop-off – Van Gogh Room – Floor M**

8.30 – 8.45 **Welcome**
*Julie Raskin, Congenital Hyperinsulinism International (CHI),
Maureen Bakker and Wende, Netherlands Parent Support Group and Ulrike Seyfarth, Kongenitaler
hyperinsulinismus e.V*

8.45 - 9.05 **"Dare to Dream: A Vision for a Future without Lows"**
Presenter: Charles Stanley, MD, Children's Hospital of Philadelphia

9.05 – 9:45 **HISTories – Family Presentations on Life with HI**
*Presenters: Teenagers and Young Adults with HI - Max Aronoff-Sher, Connie Lee Ward, Anna
Nicolaou, Paul Seyfarth, and Stella Promussas*

9.45 - 10.15 **Current and Future Medical Treatments**
Presenters: Diva De León-Crutchlow, MD, Children's Hospital of Philadelphia

10.15 – 10.45 **Group Photo and Networking Break**

10.45 - 11.35 **CHI Centers of Excellence**
Quality and Patient Experience - *Indi Banerjee, NORCHI, MD*
Research - *Antonia Dastamani, MD, Great Ormond Street Hospital*
Integrated Multidisciplinary Team - *Diva De León-Crutchlow, MD, Children's Hospital of
Philadelphia*
Surgery and Advanced Radiology Technologies - *Peter Kuhnen, MD or Oliver Blankenstein, MD,
Charite*
Neonatal hypoglycaemia – *Sebastian Kummer, MD, University Children's Hospital Düsseldorf*
Interinstitutional-Multidisciplinary Team - *Klaus Mohnike, MD, COACH
Paul Thornton, MD, Cook Children's*

- 11.35 – 12.35** **The Role of Advocacy in Advancing Compassionate Care for Children with HI (With guided discussion to better understand the need for compassion across the milestones of the HI experience.)**
Presenter: Sir Albert Aynsley-Green, MD
- 12.35 - 13.35** **Networking Lunch – Gallery Restaurant**
- 13.35 - 14.05** **Congenital Hyperinsulinism (HI) in the Netherlands
A Conversation
Diagnosis, Treatment, and Advocacy**
Presenter: Mirjam van Albada, MD, University of Groningen
The Road to a Patient Organization in the Netherlands
Hajo Wildschut, MD, HI Grandfather and Obstetrician
- 14.05 - 14.50** **Hyperinsulinism Global Advocacy - Patient-driven global initiatives
CHI International, the HI Global Registry, and CHI Collaborative Research Network,
Kongenitaler hyperinsulinismus e.V,**
Presenters: Tai Pasquini, PhD, CHI, Indi Banerjee, MD, NORCHI, Julie Raskin, Janet Lee, Sandra Melo, Ulrike Seyfarth
- 14.50 – 15.30** **Learning about Clinical Research from People in the Biotechnology Field**
Hanmi, Rezolute, and Zealand
- 15.30 – 16.15** **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
- Panelists:*
Sir Albert Aynsley-Green, MD, Emeritus, University College London
Indi Banerjee, MD, Royal Manchester Children’s Hospital
Oliver Blankenstein, MD, Charite Hospital
Henrik Christesen, MD, Hans Christian Anderson Children’s Hospital
Antonia Dastamani, MD, Great Ormond Street Hospital
Diva De León-Crutchlow, MD, Children’s Hospital of Philadelphia
Huseyin Demirbilek, MD, Hacettepe University
Clare Gilbert, Clinical Nurse Specialist, Great Ormond Street Hospital
Sebastian Kummer, MD, University Children’s Hospital Düsseldorf
Peter Kühnen, MD, Charite Hospital
Thomas Meissner, MD, University Children’s Hospital Düsseldorf
Kate Morgan, Clinical Nurse Specialist Great Ormond Street Hospital
Elizabeth Rosenfeld, MD, Children’s Hospital of Philadelphia

Charles Stanley, MD, Children's Hospital of Philadelphia
Mirjam van Albada, MD, University of Groningen
Chris Worth, MD, Royal Manchester Children's Hospital
And Biotech Speakers

16.15 – 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
Young adults

19.00 - 21.00 **Dinner, Drinks and Live Music – Gallery Restaurant**

Sunday, September 24, 2023

All Sessions will take place in the Rembrandt Room on Floor M

8.15 **Babysitting Registration and drop-off – Vermeer Room – Floor M**

8.30 - 9.00 **Welcome – Executive Suite - Floor 9**

9.00 - 9.45 **HISTories - Family Presentations on Life with HI**
Presenters: Jessica Aronoff, Maureen Bakker (Moderator), and Marina Lozancic

9.45 – 10.05 **Diet and HI**
Should diet play a role in managing congenital hyperinsulinism by HI type? If so, how?
Presenters: Thomas Meissner, MD, University Children's Hospital Düsseldorf

10.05 - 10.50 **Quality of Life Research and Discussion**
Overview of Research on Quality of life from Düsseldorf and CHI
Presenters: Marcia Roeper, MD, University Children's Hospital Düsseldorf,
Tai Pasquini, PhD, Lora Van Arsdell, PsyD, CHI

10.50 - 11.15 **Networking Break**

11.15 - 12.00 **Large Group Discussion – What are the Biggest Quality of Life Issues with HI at Each Stage of Life?**

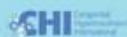
By Age and Phase of Life
Baby/Toddler
School Aged
Teens
Adults
Grandparents

12.00 **Closing Remarks**

12.15 **Light Lunch-Optional – Gallery Restaurant**

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Panelists, Presenters and Moderators



Max Aronoff-Sher

Person with HI
Santa Monica, California

Sir Albert Aynsley-Green, MD

Pediatric Endocrinologist
Former President, British Medical Association
Former Children's Commissioner
Salisbury, United Kingdom

Indi Banerjee, MBBS, MD, MRCPCH

Pediatric Endocrinologist, Royal Manchester Children's
Hospital
Clinical Lead, Northern Congenital Hyperinsulinism
Service (NORCHI)
Manchester, United Kingdom

Oliver Blankenstein, MD

Pediatric Endocrinologist
Medical Director, Charité
Berlin, Germany

Antonia Dastamani, MD, PhD

Pediatric Endocrinologist, Great Ormond Street Hospital
(GOSH)
London, United Kingdom

Diva D. De León-Crutchlow, MD, MSCE

Pediatric Endocrinologist, Chief of the Division of
Endocrinology and Diabetes
Director of the Congenital Hyperinsulinism Center, Childrens
Hospital of Philadelphia (CHOP)
Philadelphia, PA

Huseyin Demirbilek, MD

Pediatric Endocrinologist and Associate Professor at
Hacettepe University
Ankara, Turkey

Clare Gilbert, RN

Pediatric Endocrinology Advanced Nurse, GOSH
London, United Kingdom

Peter Kuhen, MD

Director of Pediatric Endocrinology Department, Charité
Berlin, Germany

Sebastian Kummer, MD

Pediatric Endocrinologist, University Children's Hospital
Duesseldorf, Germany

Janet Lee

HI Parent
Brighton, United Kingdom

Connie Ward Lee

HI Patient
Brighton, United Kingdom

Thomas Meissner, MD

Deputy Director Department of General Pediatrics,
Neonatology and Pediatric Cardiology, University Children's
Hospital Düsseldorf
Düsseldorf, Germany

Klaus Mohnike, MD

Pediatric Endocrinologist, Otto-von-Guericke
Universität Magdeburg
Magdeburg, Germany

Anna Nicolaou

Person with HI
Brighton, United Kingdom

Stella Promussas

HI Patient
Vienna, Austria

Julie Raskin, MA

HI Parent
Executive Director, CHI
Glen Ridge, NJ

Henrik Thybo Christesen, MD, PhD

Pediatric Endocrinologist
Consultant and Professor, Hans Christian Andersen Children's
Hospital, Odense University Hospital
Odense, Denmark

Marcia Roeper, MD

Pediatric Endocrinologist, University Children's Hospital
Düsseldorf
Düsseldorf, Germany

Elizabeth Rosenfeld, MD

Pediatric Endocrinologist, CHOP
Philadelphia, PA

Sandra Silva Melo, PsyD

HI Parent
Setubal, Portugal

Charles Stanley, MD

Pediatric Endocrinologist, Founder of the HI Center, CHOP
Professor Emeritus of Pediatrics, University of Pennsylvania
Perelman School of Medicine
Philadelphia, PA

Paul Thornton, MD

Medical Director, Hyperinsulinism Center and Endocrine and
Diabetes Program, Cook Children's Medical Center
Fort Worth, TX

Tai Pasquini, MPA, PhD

Chief Research Officer, CHI
East Longmeadow, MA

Paul Seyfarth

HI Patient
Berlin, Germany

Ulrike Seyfarth

HI Parent and Sibling,
President, Kongenitaler Hyperinsulinismus e.V.
Berlin, Germany

Mirjam van Albada, MD

Pediatric Endocrinologist, University of Groningen
Groningen, Netherlands

Lora Van Arsdell-Bartocci, PsyD, LCSW

Research and Support Specialist, CHI
HI Parent and Psychologist
Nolanville, TX

Maureen Van Nooijen-Bakker

HI Parent
Zwaag, Netherlands

Hajo Wildschut, MD

HI Grandfather and Obstetrician
Enkhuizen, Netherlands

Christ Worth, MD, PhD Candidate

Pediatric Endocrinologist, Royal Manchester Children's
Hospital
Manchester, United Kingdom

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in The Hague

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