2023 CONGENITAL HYPERINSULINISM
FAMILY CONFERENCE IN THE HAGUE
September 22 - 24, 2023
The Hague Marriott
Johan de Wittlaan 30, The Hague

Organized by:
Congenital Hyperinsulinism International with the Netherlands Parent Support Group and Kogenitaler 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, Kogenitaler 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
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**
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 Hyperinsulinmismus 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

Thank you to the sponsors of the 2023 Congenital Hyperinsulinism Family Conference in The Hague

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