



First Department of Pediatrics  
Medical School  
National and Kapodistrian  
University of Athens



**2018 Congenital Hyperinsulinism Family Conference**  
**Athens, Greece**  
**The Wyndham Grand Athens Hotel**  
**September 25-26, 2018**

Sponsored by:

The Medical School of the National Kapodistrian University of Athens and  
Congenital Hyperinsulinism International

Day 1

25<sup>th</sup> of September 2018

**8.15-9.00 Registration**

**9.00-9.15 Introduction-Welcome**

George Chrousos, MD, Professor and Chairman of the First Department of Pediatrics, Medical School, National and Kapodistrian University of Athens, "Agia Sophia" Children's Hospital, Athens, Greece

Christina Kanaka Gantenbein, MD, Professor of Pediatric Endocrinology, First Department of Pediatrics, Medical School, National and Kapodistrian University of Athens, "Agia Sophia" Children's Hospital, Athens, Greece

Julie Raskin, Executive Director, Congenital Hyperinsulinism International, Montclair, NJ, USA

**SESSION 1: DIAGNOSIS OF CONGENITAL HYPERINSULINISM**

Conference Moderators: Pratik Shah, MD, PhD, Pediatric Endocrinologist, GOSH, London, UK

Christina Kanaka Gantenbein, MD, Professor of Pediatric Endocrinology, First Department of Pediatrics, Medical School, National and Kapodistrian University of Athens, "Agia Sophia" Children's Hospital, Athens, Greece

**9.15 Guidelines for Detecting Hypoglycemia**

Paul Thornton, MD, Medical Director, Endocrine and Diabetes, and Hyperinsulinism Center, Cook Children's, Fort Worth, TX, USA

**9.30 The Role of Insulin in the Human Body and The Mechanism of Disease with Congenital Hyperinsulinism**

Indi Banerjee, MD, Consultant in Pediatric Endocrinology at the Royal Manchester Children's Hospital and Clinical Lead for the Northern Congenital Hyperinsulinism Service (NORCHI), Manchester, UK

**9:45 Diagnosing Congenital Hyperinsulinism**

**To be determined**

**10.00-10.30 The Genetics of Congenital Hyperinsulinism**

Sian Ellard, PhD, Head of Molecular Genetics, Royal Devon & Exeter NHS Foundation Trust and Professor of Human Molecular Genetics, University of Exeter Medical School, Exeter, UK

**10.30-11.00 Imaging in the Diagnosis of Congenital Hyperinsulinism**

Maria Gavra, MD, Department of Neuroradiology, "Agia Sophia" Children's Hospital, Athens, Greece

**11.00-11.30 Coffee break**

## **SESSION 2: TREATMENT OF CONGENITAL HYPERINSULINISM**

Moderators: Prof. Assimina Galli-Tsinopoulou, Pediatric Endocrinologist, Aristotle University, Thessaloniki, Greece  
Henrik Christesen, Pediatric Endocrinologist, Odense Children's Hospital, Odense, Denmark

**11.30-12.15 Old and New Medical Treatments for Congenital Hyperinsulinism and Surgical Treatment**

Senthil Seniappan, MD, PHD, Consultant in Pediatric Endocrinology at Alder Hey Hospital, Liverpool, UK, Charles Stanley, MD, Founder of the Congenital Hyperinsulinism Center at the Children's Hospital of Philadelphia, Philadelphia, Oliver Blankenstein, MD, Pediatric Endocrinologist, Charite Hospital, Berlin, Germany

**12.15-13.00 Feeding Issues and Nutrition**

Oliver Blankenstein, Pediatric Endocrinologist, Charite Hospital, Berlin, Germany

**13.00-14.00 Lunch**

## **SESSION 3: DAY-TO-DAY CARE OF CHILDREN WITH CONGENITAL HYPERINSULINISM**

Moderators: Irene Promussas, President, Lobby 4 Kids, Vienna, Austria  
Antonia Dastamani, MD, Pediatric Endocrinologist, GOSH, London, UK

**14.00-15.00 Extreme Parenting – HIStories**

HI Family Speakers – To Be Determined

**15.00-15.20 Managing HI at School and Daycare**

Cristina Pindado, Chairperson, AFHICO, Barcelona, Spain

**15.20-15.40 What's New with Devices, Glucometers and Continuous Glucose Monitoring Systems**

Madhini Sivasubramanian, Senior Lecturer, University of East London  
Research Nurse Specialist in Congenital Hyperinsulinism, GOSH, London, UK

**15.40 Sick Day Management of Congenital Hyperinsulinism**

Sebastian Kummer, MD, Department of General Pediatrics, Neonatology and Pediatric Cardiology, University Children's Hospital Düsseldorf, Germany

**16.00-16.30    Networking break**

**SESSION 4: PSYCHOSOCIAL ISSUES**

Moderators: Davelyn Hood, MD, MBA, President of the Board of Directors of Congenital Hyperinsulinism International

Ulrike Seyfarth, President of Kongenitaler Hyperinsulinsimuse.V, Berlin Germany

**16.30-17.00    The Psychosocial Burden of Congenital Hyperinsulinism**

Clare Gilbert and Hannah Antell, Congenital Hyperinsulinism Clinical Nurse Specialist, GOSH, London, UK

Julie Raskin, Congenital Hyperinsulinism International

**17.00-17.45    Coping Strategies for Parents of Children with Congenital Hyperinsulinism**

Irene Prosmussas, President, Lobby 4 Kids, Vienna, Austria, Member of Kongenital Hyperinsulinismus e.v.

Clare Gilbert and Hannah Antell, Congenital Hyperinsulinism Clinical Nurse Specialist, GOSH, London, UK

**17.50-18.15    Summary of the Day**

**19.30            Dinner**

Day 2

26<sup>th</sup> of September 2018

**SESSION 5: FROM THE CONGENITAL HYPERINSULINISM ACADEMIC COMMUNITY**

Moderators: **TBD**

Pratik Shah, MD, PhD, Pediatric Endocrinologist, GOSH, London, UK

**8.30-9.30       Long-term Outcome in Patients with Congenital Hyperinsulinism**

- Neurocognitive function (From prolonged hyperinsulinism and HIHA) and Quality of Life

Klaus Mohnike, MD, Pediatric Endocrinologist, Otto von Guericke University Magdeburg, Germany

- Transition from Pediatric to Adult Care

Pratik Shah, MD, PhD, Pediatric Endocrinologist, GOSH, London, UK

Kate Morgan, Congenital Hyperinsulinism Clinical Nurse Specialist, GOSH, London, UK

**9.30-10.40    Recent International Academic Research**

Indi Banerjee, MD, Consultant in Pediatric Endocrinology at the Royal Manchester Children's Hospital and Clinical Lead for the Northern Congenital Hyperinsulinism Service (NORCHI)

Oliver Blankenstein, MD, Pediatric Endocrinologist, Charite Hospital, Berlin, Germany  
Henrik Christesen, MD, Pediatric Endocrinologist, Odense Children's Hospital, Odense, Denmark  
Nino Kheladze, MD, M. Iashvili Children's Hospital, Tbilisi, Georgia  
Sebastian Kummer, MD, Department of General Pediatrics, Neonatology and Pediatric Cardiology, University Children's Hospital Düsseldorf, Germany  
Klaus Mohnike, MD, Pediatric Endocrinologist, Otto von Guericke University Magdeburg, Germany  
Senthil Seniappan, MD, PhD, Consultant in Pediatric Endocrinology, Alder Hey Hospital Liverpool, UK  
Pratik Shah, MD, PhD, Pediatric Endocrinologist, GOSH, London, UK  
Charles Stanley, MD, Founder of the Congenital Hyperinsulinism Center at the Children's Hospital of Philadelphia, Philadelphia, PA, USA  
Paul Thornton, MD, Medical Director, Endocrine and Diabetes, and Hyperinsulinism Center, Cook Children's, Fort Worth, TX, USA  
David Zangen, MD, Pediatric Endocrinologist, Hadassah Hospital, Jerusalem, Israel

**10.40-11.10 Congenital Hyperinsulinism Case Studies**

Antonia Dastamani, MD, Pediatric Endocrinologist, GOSH, London, England, Eirini Kostopoulou, MD, Pediatric Endocrinologist, Department of Pediatrics, University of Patras, Patras, Greece

**11.10-11.40 Networking break**

**SESSION 6: FROM THE CONGENITAL HYPERINSULINISM PATIENT COMMUNITY**

**11.40-13.00 Patient-Powered Research, Awareness Campaigns, Access to medication, care, and supplies, Patient Support and Quality of Life**

Davelyn Hood, MD, MBA, President of the Board of Directors of Congenital Hyperinsulinism International, San Antonio, TX, USA, Ulrike Seyfarth, Germany, President of Kongenitaler Hyperinsulinsimuse.V, Berlin Germany, Julie Raskin, Executive Director, Congenital Hyperinsulinism International

**13.00-14.00 Lunch**

**SESSION 7: NEW ADVANCES IN THE TREATMENT OF CONGENITAL HYPERINSULINISM FROM THE BIOTECH COMMUNITY**

Moderators: Paul Thornton, MD, Medical Director, Endocrine and Diabetes, and Hyperinsulinism Center, Cook Children's, Fort Worth, TX, USA  
Klaus Mohnike, MD, Pediatric Endocrinologist, Otto von Guericke University Magdeburg, Germany

**14.00-15.00 Ongoing and New Projects from the Biotech Community**

Christina Ferrara, MD, PhD, Rezolute, Klara Owen, MD, Zealand

**SESSION 7: ASK THE EXPERTS**

**15.00:16.00** All the Conference Specialists

**16.00-16.30** Summary of the conference-Closing remarks