



Congenital Hyperinsulinism Family Conference
September 8-9, 2016
FIAP
Paris, France

Thursday, September 8, 2016

- 7:45 am** **Registration**
- 8:20 am** **Welcome and Introductions**
Jean-Baptiste Arnoux, MD, Necker Hospital, Paris, France
Isabel Calderón and Julie Raskin, Congenital Hyperinsulinism International (CHI)
Conference Moderators
- 8:30 am** **Hyperinsulinism Retrospective**
Joseph Bryan, PhD, Pacific Northwest Diabetes Research Institute. Seattle, WA, US, Charles Stanley, MD, Children's Hospital of Philadelphia (CHOP), US
- 9:10 am** **How to Recognize and Diagnose Hypoglycemia in Infants**
Paul Thornton, MD, Cook Children's, Fort Worth, TX, US
- 9:35 am** **Understanding the Genetics of Hyperinsulinism**
Sian Ellard, PhD, FRCPath, Head of Molecular Genetics, Royal Devon & Exeter NHS Foundation Trust and Professor of Human Molecular Genetics, University of Exeter Medical School, UK
- 10:15 am** **Break**
- 10:35 am** **Current Treatment**
- **Medical Options** *Jean-Baptiste Arnoux, MD, Necker Hospital*
 - **"PET Scan – A Powerful Tool"**
Prof Françoise Montravers, MD, Necker Hospital, Paris, France
 - **Surgical Update in the Treatment of Hyperinsulinism**
Carmen Capito, MD, Necker Hospital, Paris, France
- 11:35 am** **What's New in the World of Glucometers, CGMs, and Insulin Pumps?**
Dr Cécile Godot, MD, Necker Hospital, Paris, France
- 12:00 pm** **Patients and their Families Share Triumphs and Challenges**
Moderators: Isabel Calderón and Julie Raskin, CHI

Topics: Feeding
Visiting with friends and relatives
School
Sports participation
Parents going back to work
Transition to Adulthood
Letting Go

1:00 pm **Lunch**

2:00 pm **Coping Strategies for Managing the Stress of Caring for Children with Complex Medical Needs**
Moderator: Isabel Calderón, CHI
Elisabeth Ouss, MD, Necker Hospital, Paris, France
Irene Promussas, Lobby4kids and Kongenitaler Hyperinsulinismus. e.V., Vienna, Austria

3:00 pm **CHI Centers of Excellence Designation-- Highlighting Evidence-based Approaches to Care at Leading Centers Around the World**
Moderator: Davelyn Hood, CHI, MD, MBA
Presenters: Jean-Baptiste Arnoux, MD, Necker Hospital, Paris, France, Henrik Christesen, MD, Odense University Hospital, Odense, Denmark, Paul Thornton, MD, Cook Children's, Fort Worth, TX, US, Dr. Charles Stanley, MD, CHOP, Philadelphia, PA, US, Klaus Mohnike, MD, University of Magdeburg, Magdeburg, Germany, Winfried Barthlen, MD, Greifswald University, Germany, Sebastian Kummer, MD, University Children's Hospital Duesseldorf, Duesseldorf, Germany, Oliver Blankenstein, MD, Charite, Berlin, Germany, Pratik Shah, MD, Great Ormond Street Hospital (GOSH), London, England

4:10 pm **Networking Break**

4:30 pm **Concurrent Sessions: Learning More about Different Types of Congenital Hyperinsulinism**

Diazoxide-Responsive Congenital Hyperinsulinism
Focal Congenital Hyperinsulinism
GDH Congenital Hyperinsulinism
Congenital Hyperinsulinism and Diabetes
Non-diazoxide Responsive Hyperinsulinism and Still Hypoglycemic

Jean Baptiste-Arnoux, MD, Necker
Oliver Blankenstein, MD, Charite
Clare Gilbert, Clinical Nurse Specialist, GOSH
Klaus Mohnike, MD, Magdeburg

Charles Stanley, MD, CHOP
Paul Thornton, MD, Cook Children's
Pratik Shah, MD, Great Ormond Street Hospital (GOSH)
Henrik Christesen, MD, Odense University, Odense

- 5:30 pm** **Adjourn**
- 7:00 pm** **Dinner and Discussion with musical performance by singer/songwriter, Janna Pelle**

Friday, September 9, 2016

- 8:30 am** **Registration, Day 2**
- 8:45 am** **Global Access to Treatments, Medications and Supplies**
Moderator: Julie Raskin, CHI
Presenters: Jean-Baptiste Arnoux, Necker, Nino Kheladze, MD, M. Iashvili Children's Hospital, Tbilisi, Georgia
- 9:30 am** **Recent International Academic and Patient-Powered Research**
Moderator: Jean-Baptiste Arnoux, Necker
Université Paris Descartes (Latif Rachdi, MD), CHOP (Charles Stanley, MD), Charite (Oliver Blankenstein, MD), Cook (Paul Thornton, MD), Odense University (Henrik Christesen, MD), Magdeburg (Klaus Mohnike)
- 10:30 am** **Networking Break**
- 10:45 am** **Recent International Academic and Patient-Powered Research (Continued)**
Moderator: Jean-Baptiste Arnoux, Necker
CHI (Davelyn Hood, MD, MBA), e.V. Hyperinsulinismus (Ulrike Seyfarth), Manchester (Mark Dunne, PhD), University of Greifswald (Winfried Barthlen, MD), Alder Hey Children's Hospital, Liverpool (Senthil Senniappan MD, PhD), Great Ormond Street Hospital (Pratik Shah, MD and Clare Gilbert, Clinical Nurse Specialist)
- 11:50 am** **Patients in Action – Creative Approaches to Raising Awareness and Supporting HI Families**
Moderator – Isabel Calderón, CHI
Vincent Picard, Association des hyperinsulinismes – France, Cristina Pindado, President of Hiperinsulinismo Congénito - Afhico, Janna Pelle, Social Media Guru, CHI, Ulrike Seyfarth, Hyperinsulinismus e.V.
- 12:30 pm** **Insulin Action and Associated Disorders**
Sebastian Kummer, MD, University Children's Hospital Duesseldorf, Duesseldorf, Germany

- 1:00 pm** **Lunch**
- 2:00 pm** **Investigational Projects from the Biotech Community (Some of the presenters are from academic institutions)**
Moderator: Davelyn Hood, CHI, MD, MBA
The BetaCure Project - Oliver Blankenstein, MD, Marti Boss, XOMA - Kirk Johnson, PhD, Xeris - Paul Thornton, MD
- 2:40 pm** **Speed Dating with the Specialists (Your chance to ask leading experts whatever you want to know about hyperinsulinism. Every 15 minutes, participants will switch groups)**
- These are possible discussion topics but conversation is open:**
Transition from Pediatric to Adult Care
Challenges to Managing HI in infants and Toddlers
HI and Growth and Development
When Hypoglycemia is Still an Issue
Transition from Pediatric to Adult Care
When Genetics are a Mystery
- Moderators: Isabel Calderon, Davelyn Hood, Julie Raskin*
Faculty: Jean-Baptiste Arnoux, MD, Joseph Bryan, PhD, Sebastian Kummer, MD, Winfried Barthlen, MD, Mark Dunne, PhD, Oliver Blankenstein, MD, Françoise Montravers, MD, Klaus Mohnike, MD, Carmen Capito, MD, Charles Stanley, MD, Pratik Shah, MD, Paul Thornton, MD, Winfried Barthlen, MD, Henrik Christesen, MD, Senthil Senniappan MD, PhD
- 3:40 pm** **Networking Break**
- 4:00 pm** **Congenital Hyperinsulinism: From Infancy to Adulthood**
A. Challenges to Managing HI including feeding in Infants and Toddlers
Oliver Blankenstein, MD and Isabel Calderon, CHI
B. Managing HI at School
Kanetee Busiah, MD, Necker Hospital
C. New Treatments for Diabetes
Jacques Beltrand, MD, Necker Hospital
- 4:30 pm** **Closing Remarks and Adjourn**