



5th Congenital Hyperinsulinism Family Conference
September 17-18, 2013
NH Milano 2 Hotel
Segrate, Italy

Tuesday, September 17, 2013

- 9:00 a.m. Registration**
- 9:30 a.m. Opening Remarks**
Julie Raskin, Congenital Hyperinsulinism International
- 9:40 a.m. The Patient Voice - The Work and Role of Patient Organizations:
Developing a Global Platform for Congenital Hyperinsulinism Patients**
*Irene Promussas, Ph.D., Kongenitaler Hyperinsulinimus.e.V (Lobby4kids);
Adrienne Burton, The HI-Fund; Isabel Calderon, Congenital Hyperinsulinism
International*
- 10:30 a.m. The History of Congenital Hyperinsulinism Treatment and Research
Highlighting Breakthroughs**
Paul Thornton, M.D., Cook Children's Hospital, Fort Worth, Texas
- 11:00 a.m. Morning Break**
- 11:15 a.m. Congenital Hyperinsulinism Genetics 101**
Khalid Hussain, M.D., Great Ormond Street Hospital, London, England
- 11:45 a.m. PET Scan in Practice for Congenital Hyperinsulinism Diagnosis**
*Oliver Blankenstein, Charite Hospital, Berlin, Germany
Klaus Mohnike, M.D., Magdeburg Hospital, Magdeburg, Germany (COACH)
Clare Gilbert, R.N., Great Ormond Street, London, England
David Langdon, M.D., Children's Hospital of Philadelphia, Philadelphia, U.S.*
- 12:45 p.m. Lunch**
- 1:45 p.m. Research Report from Manchester: Fish Oil**
*Louise Caine, Specialist Nurse, Royal Manchester Children's Hospital,
Manchester, England*

- 2:10 p.m. Research Report from Magdeburg: Longitudinal Follow-up Studies of Congenital Hyperinsulinism Patients Including Psychometric Studies**
Klaus Mohnike, M.D., Magdeburg Hospital, Magdeburg, Germany (COACH)
- 2:35 p.m. XMETD: Investigational Drug for the Treatment of Congenital Hyperinsulinism**
Paul Rubin, M.D., XOMA, Berkeley, CA, U.S.
- 3:00 p.m. Research Report from the Children's Hospital of Philadelphia**
David Langdon, M.D., Children's Hospital of Philadelphia, Philadelphia, U.S.
- 3:25 p.m. Research Report from University Children's Hospital Dusseldorf: Remission in Non-Operated Patients with Diffuse Disease and Long-term Conservative Treatment.**
Thomas Meissner, M.D., University Children's Hospital Dusseldorf, Dusseldorf, Germany
- 3:50 p.m. Break**
- 4:00 p.m. Concurrent Session: Learning More about Different Types of Congenital Hyperinsulinism (The endocrinologists and nurses will be assigned to the different groups and will moderate the discussions.)**
- Diazoxide-Responsive Congenital Hyperinsulinism
Focal Congenital Hyperinsulinism Forum
GDH Congenital Hyperinsulinism
Congenital Hyperinsulinism and Diabetes
Surgery and Still Hypoglycemic**
- 5:00 p.m. Wrap-up**
- 7:00 p.m. Family Dinner**

Wednesday, September 18, 2013

- 9:00 a.m. Histories: Congenital Hyperinsulinism Families, Children and Teenagers Share Their Experiences**
- 10:00 a.m. Managing Congenital Hyperinsulinism at School**
Clare Gilbert, R.N., Great Ormond Street Hospital, London, England
- 10:45 a.m. Morning Break**
- 11:00 a.m. Devices: What's New and What Works**
Glucometers, CGMs, Pumps, G-tubes
*Clare Gilbert, R.N., Great Ormond Street Hospital, London, England
Adrienne Burton, HI-Fund, London, England*
- 11:30 a.m. Feeding Issues Panel**

Oliver Blankenstein, M.D., Charite Hospital, Berlin, Germany
Clare Gilbert, R.N., Great Ormond Street Hospital, London, England
Isabel Calderon – Parent, Clarke City, Quebec, Canada and Vice President,
Congenital Hyperinsulinism International

- 12:30 p.m. Lunch**
- 1:30 p.m. Coping Strategies for Managing the Stress of Caring for Children with Complex Medical Needs**
Irene Promussas, Ph.D., Kongenitaler Hyperinsulinimus.e.V (Lobby4kids)
- 2:00 p.m. Research Report from Greifswald: Highly Selective Surgery in Focal and Non-focal Congenital Hyperinsulinism and Functional Measurement of Islet Insulin Secretion During Surgery for Congenital Hyperinsulinism.**
Winfried Barthlen, M.D., Ph.D., Greifswald Hospital, Greifswald, Germany (COACH)
- 2:30 p.m. Investigational Drug for Diffuse Disease: Recent Research from Great Ormond Street**
Senthil Senniappan, M.D., Great Ormond Street Hospital, London, England
- 3:00 p.m. Recent Research on Long Acting Octreotide**
Oliver Blankenstein, M.D., Charite Hospital, Berlin, Germany
Pratik Shah, M.D., Great Ormond Street Hospital, London, England
- 3:45 p.m. Wrap up**