



**5<sup>th</sup> 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, M.D., 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*  
*Winfried Barthlen, M.D., Ph.D., Greifswald Hospital, Greifswald, Germany (COACH)*  
*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.*
- 1:00 p.m. Lunch**

- 2:00 p.m. Research Report from Manchester: Fish Oil**  
*Louise Caine, M.D., Royal Manchester Children's Hospital, Manchester, England*
- 2:20 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)*
- 2:40 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 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)*
- 3:20 p.m. Research Report from the Children's Hospital of Philadelphia**  
*David Langdon, M.D., Children's Hospital of Philadelphia, Philadelphia, U.S.*
- 3:40 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*
- 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 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. Congenital Hyperinsulinism as We Experience It**  
***Children and teenagers with the condition share their experiences***
- 12:15 p.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*
- 1:00 p.m. Lunch**
- 2:00 p.m. Coping Strategies for Managing the Stress of Caring for Children with Complex Medical Needs**  
*Irene Promussas, M.D., Lobby4kids*
- 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**