Congenital Hyperinsulinism International

Improving the lives of children, adults, and families living with congenital hyperinsulinism around the world

5th Family conference – Segrate, Italy – 17 septembre 2013
CHI - Who we are

- Organization founded in 2005 by concerned parents dedicated to improving the lives of HI families;
  - 9 board members (Canada, USA, Australia)
  - 1 director – Julie Raskin

- Scientific advisory group: 12 of the leading HI specialists
What we do

• Advocate on behalf of children and adults with congenital hyperinsulinism
• Create and provide educational resources to patients, families, medical professionals, school personnel, and any other interested parties
• Support research and development of medical knowledge and medical devices to better understand and treat congenital hyperinsulinism
• Support children, adults, and their families living with congenital hyperinsulinism
• Increase awareness of congenital hyperinsulinism, especially among medical personnel, in order to improve timely diagnosis
What we have done

• Support initiatives to improve timely diagnosis (screening of newborns)
• Family conferences and meetings (9)
• Help families from all over the world get to leading treatment centers (China, Argentina, Russia, India, Dominican Republic, USA)
• Work with industry on development of treatments
• Support research
• Raise awareness, provide information and support, work with other rare disease orgs., develop patient registry, and more...
Some of the challenges we face

• Reaching out to families without Internet access
• Families with no access to medication or specialized care
• Holistic approach to caring for HI patients
• HI awareness and timely diagnosis
Putting our strengths together to ...

- Reach out to more families around the world
- Increase global access to excellent HI care
- Increase physician awareness of HI
- Raise more funds for research
How can we do that

• Networking with allied patient organizations
• Involving families
• Having volunteers from many countries