

# Congenital Hyperinsulinism International



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

5th Family conference – Segrate, Italy – 17 settembre 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