



Cook Children's Hyperinsulinism Center

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What we do and what you can do

- Research
- Teaching
- Advocacy

Research

- Local level
 - Working with neonatologists to improve care pre diagnosis
 - Improving the patient experience and the outcomes of our patients
 - Developing diagnostic protocols with referring network
 - Rapid turnaround genetic testing
- National level
 - Working with scientists/collaborators outside of our institutions to further knowledge
 - Contributing DNA specimens for testing for new diseases
- International levels
 - Utilizing the Centers of Excellence's massive experience to compare outcomes and improve quality of care

What can you do for research

- Participate locally when the opportunity presents itself
 - Be open to consider new ideas
 - Evaluate the risks of the research and the benefits for you or your child
 - Remember sometimes the benefits are not for today and for you but for tomorrow and for the community
- HIGR and Max HIGR
- Participate in fund raising through organizations that support your needs

Teaching

- Local
 - Works shops for nursing and allied health care workers on the diagnosis and management of all hypoglycemia disorders
 - Practical tips (How to do fasting studies)
- National
 - Neonatology conferences
 - Endocrine conferences
 - Pair up with start-up HI centers and help them develop
 - Host doctors who wish to learn more about hypoglycemia and its management
- International
 - Collaborative guidelines from all pediatric endocrine societies

What can you do?

- Join your local HI support group and develop educational materials in your language for other families in your country
- Support CHI in their mission to educate doctors and families
 - Glucose as a vital sign
 - Promote guidelines
- Support families who come after you
 - Be a local volunteer to come and meet the next family diagnosed with HI in your hospital

Advocacy

- Listen to Professor Albert Aynsley-Green