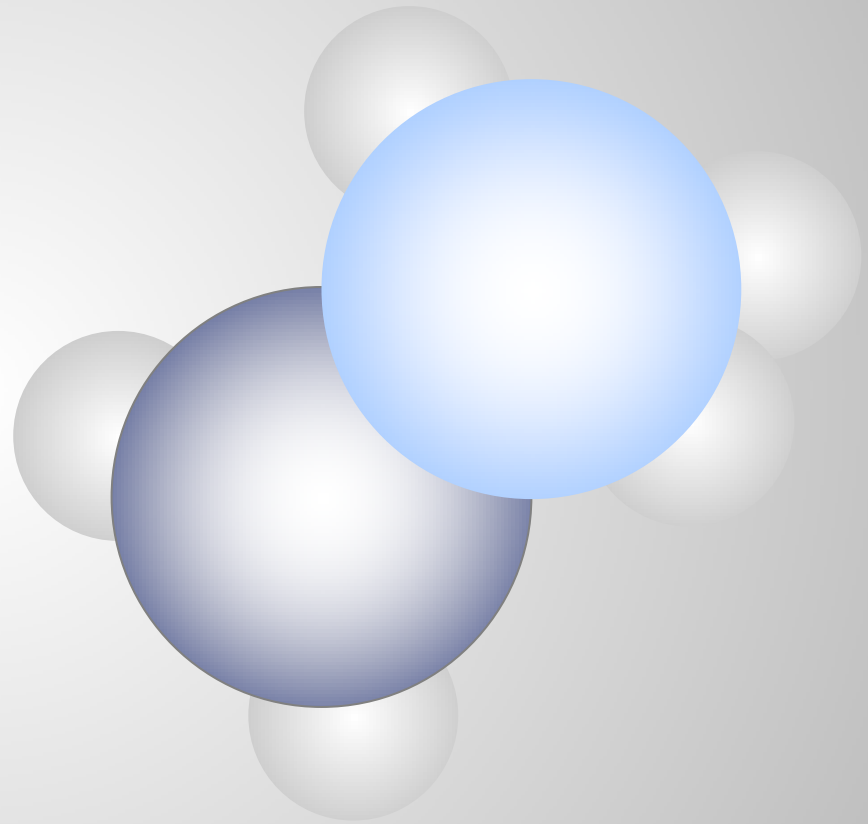


Access and Advocacy



Congenital Hyperinsulinism Family
Conference in Philadelphia
April 15-17 2016

You are part of the powerful worldwide movement called CHI



What is Advocacy?

- **Advocacy is:**
- **Supporting**
- **Recommending**
- **Championing**

A Cause – Improving the lives of people
born with congenital hyperinsulinism



By creating spaces where the community convenes and supports each other

Our online communities



By Creating spaces where the community convenes and supports each other

International Conferences



By Creating spaces where the community convenes and supports each other

International Conferences

<https://www.youtube.com/watch?v=2YV6YDmu8xM>



By creating campaigns to raise awareness of hyperinsulinism



How does CHI advocate?

By creating campaigns to raise funds for hyperinsulinism research



By championing the adoption of strong guidelines for the early detection of hyperinsulinism to reduce death and brain damage

CHI Urges Adoption of PES Hypoglycemia Guidelines

Congenital Hyperinsulinism (HI), which causes severe and prolonged hypoglycemia, can lead to brain damage and death if not detected and treated in a timely manner. Currently, many patients born with this congenital disease are discharged from newborn nurseries without adequate study of their hypoglycemia, often with tragic consequences.

In “[Recommendations from the Pediatric Endocrine Society team of experts for Evaluation and Management of Persistent Hypoglycemia in Neonates, Infants, and Children](#),” an article available online August 2015 in **Journal of Pediatrics**, the authors* provide guidelines for evaluating and managing newborn hypoglycemia. These guidelines, if widely implemented, will significantly reduce brain damage and death from hypoglycemia caused by HI. “[Re-evaluating Transitional Neonatal Hypoglycemia](#),” also published in the June 2015 **Journal of Pediatrics** by the same group of authors, clearly shows the difference between transient newborn hypoglycemia and persistent or recurrent hypoglycemia. Together, these two articles demonstrate a straightforward pathway to diagnosing hyperinsulinism before damage and death occur.

By creating a call to action for the adoption of strong guidelines for the early detection of hyperinsulinism to reduce death and brain damage

CHI Awareness: A Call to Action

CHI invites you to join us in raising awareness of HI. There are many ways. Here are some of our top suggestions:

Share the link to these guidelines: [Journal of Pediatrics: Recommendations for Evaluation and Management of Persistent Hypoglycemia](#) and [Journal of Pediatrics: Re-Evaluating Transitional Neonatal Hypoglycemia](#) with all the medical professionals you know: general pediatricians, endocrinologists, neonatologists, neurologists, obstetricians, nurses, midwives, and others. Urge newborn nurseries and neonatal intensive care units to adopt these guidelines.

Share CHI's [Statement on the Hypoglycemia Guidelines](#).

Distribute the CHI Brochure. Send a request to pamphlets@congenitalhi.org and let us know how many you can distribute and your address. We will send them to you.

Share your stories.

Take part in the **Be My Sugar** and **Raring to go for CHI** campaigns. [Instructions are here](#). You can take part any time of the year, not just leading up to Rare Disease Day.

Share [HI Videos](#).

By recognizing greatness:

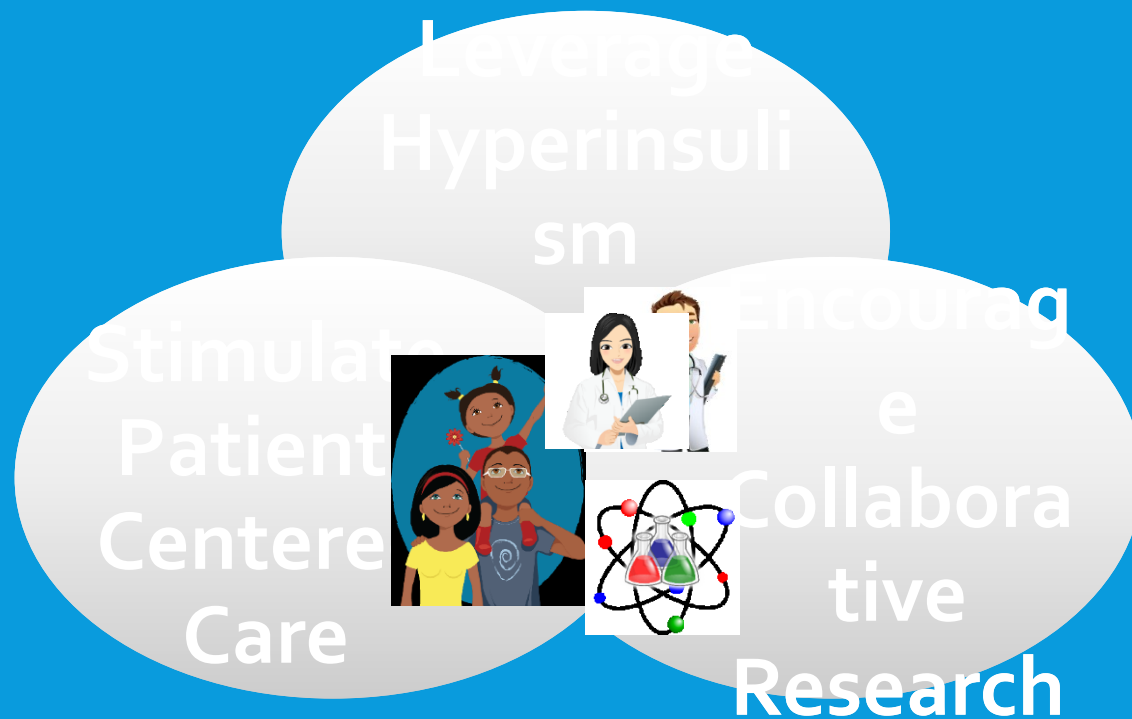


CONGENITAL HYPERINSULISM CENTERS OF EXCELLENCE



elyn Eaves Hood, MD, MBA
CHI Family Conference
Philadelphia, PA

CoE PROGRAM AIMS



DISCLAIMER



This intended to be an international program. CHI recognizes that different countries refer to specialists by different naming conventions. Furthermore, CHI recognizes that training and certification processes may differ greatly from country to country. Equivalent provider types will be accepted based on team role and function with a focus on excellent outcomes rather than specific titles.

GRADING SYSTEM



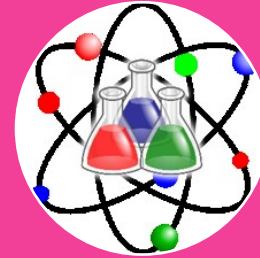
Patient-
Centered Care

60% of required points



Hyperinsulinism
Expertise

25% of required points



Collaborative
Research

15% of required points



REQUIRED ELEMENTS



Patient-Centered Care

1. Dedicated Director of Congenital Hyperinsulinism Team
2. Established Integrated Multi-Disciplinary Team
 - Primary – for diagnosis, initial treatment
 - Secondary – for ongoing HI care
 - Virtual consultation regarding HI patient who does not have access to COE
3. Comprehensive Care Coordination
4. Uses recognized guidelines for recognition and work-up of hypoglycemia
5. Inpatient care
6. Advanced technologies arrangements
7. Imaging experience
8. Surgical experience

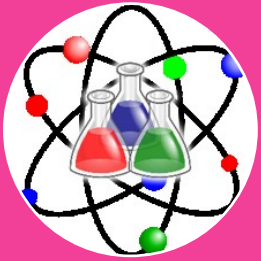
REQUIRED ELEMENTS



Hyperinsulinism Expertise

1. Actively involved in HI-relevant research
2. HI-relevant publication within three years of application
3. Provides continuing education to internal staff and local clinicians regarding HI

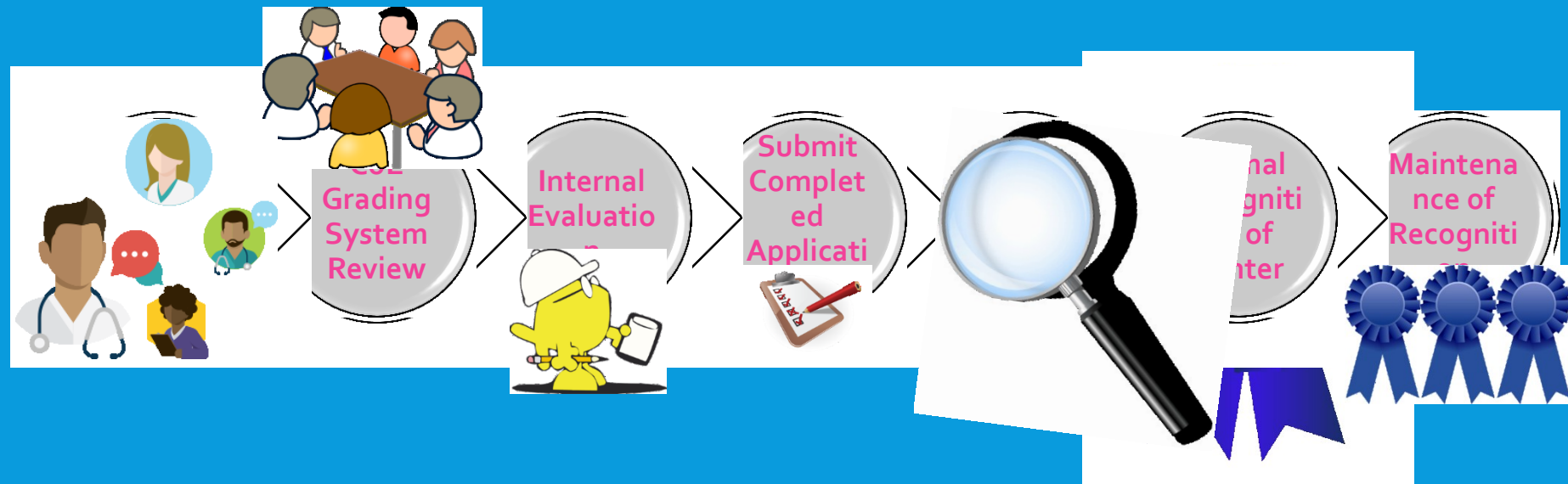
REQUIRED ELEMENTS



Collaborative Research

1. Performs HI-relevant research with researcher(s) from a facility other than own
2. Refers HI patients to the HI Global Registry

PROPOSED PROCESS



TIMELINE



QUESTIONS???



By connecting patient families to each other, advocates, medical professionals, companies and organizations to support their need for medicine, care, supplies, support, and treatment.



By working with the rare disease community to advocate for laws to keep medication costs affordable and improve the climate for the development of new rare disease therapies.

