



Congenital Hyperinsulinism International: Your Advocacy Organization



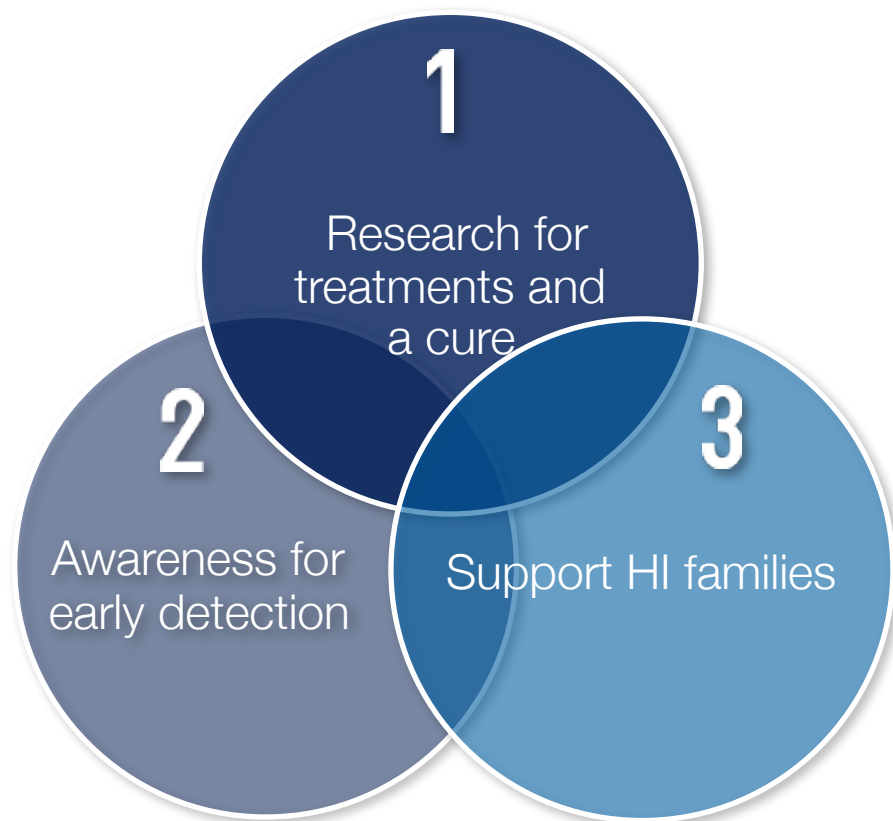
Julie Raskin
#CHIFAM2019
September 7, 2019

WHY ADVOCATE?

To support HI research for better treatments and cures,
raise awareness of HI to reduce brain damage and death,
improve access to care and treatment for those with HI,
while providing a community for HI families.



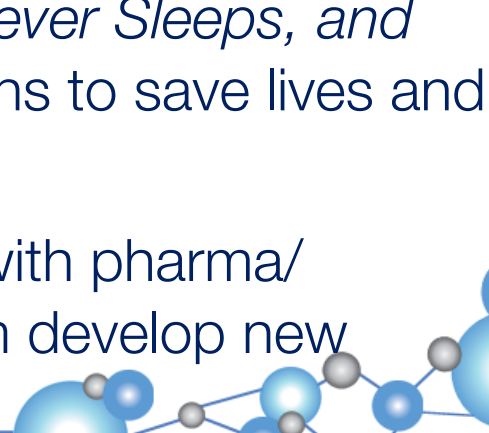
THE THREE PART MISSION



- Secured funding from a private source for a pilot clinical trial of Exendin 9-39.
- Funded or funding 3 research projects for pilot studies on drug development for a treatment for glutamate dehydrogenase hyperinsulinism.
- Funded research for a pilot study on the bihormonal bionic pancreas for the treatment of diabetes post-pancreatectomy in children with congenital hyperinsulinism.
- Funded research for pilot study on the use of sirolimus to treat hyperinsulinism.
- Funded research towards precision medicine in treatment of congenital hyperinsulinism in infancy.
- Developed the HI Global Registry which will be a key research tool to advance an understanding of the natural history of the condition and new treatments.



Since it's founding in 2005 CHI has:

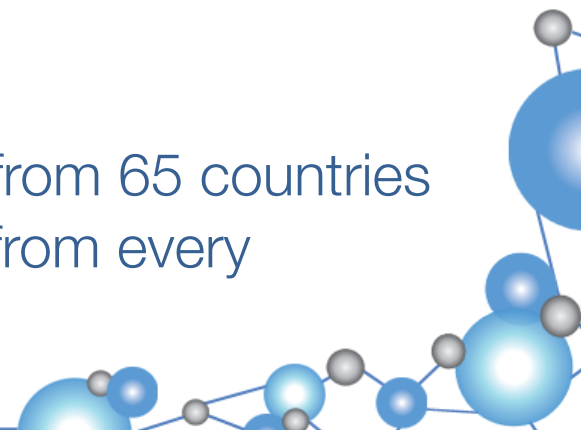
- Organized 19 HI conferences and meetings around the world bringing together leading global HI specialists to share best practices and research.
 - Widely shared and advocated for adoption of the PES Hypoglycemia Guidelines.
 - Created the global HI and hypoglycemia awareness poster campaigns to save lives and prevent brain damage. The posters are available in 19 languages.
 - Created the *Be My Sugar*, *Stop the Lows*, *HI Never Sleeps*, and *Our CHI* and many other social media campaigns to save lives and prevent brain damage.
 - Shared the patient experience in myriad ways with pharma/biotech/genetic testing companies to help them develop new treatments and products.
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- CHI has helped patients around the world receive life-saving medications, treatment and medical supplies. This year people have visited the CHI website from 123 countries.
- CHI has served as the global source of HI patient and family support.
- Support from CHI is available to the 1,400 people in the HI community around the world who are part of our online support group which is active almost 24 hours a day.
- With support from CHI, the Exeter Clinical Laboratory in the UK is providing genetic testing to patients all over the world suspected of having HI, and who do not have the ability to pay for the testing.
- CHI joined the GPED effort to have diazoxide included on the list of WHO Essential Medicines, and it was just added!

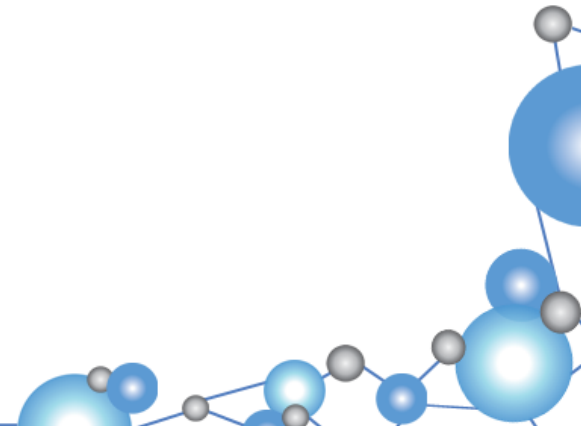


HI affects people all over the world, every race and every ethnicity. Because we are rare, global reach is so important!

- CHI communicates with endocrinologists from 43 countries.
- Through our partnership with the University of Exeter, last year, CHI funded genetic testing for people suspected of HI in 38 countries.
- CHI scientific advisors come from 7 countries.
- The CHI online support group includes people from 65 countries and the HI Global Registry participants comes from every continent.



- WE CAN'T DO THIS WITH WITHOUT YOU
(The YOU is YOU)
- Join the HI Global Registry
- Get involved
- Organize a fundraiser for CHI or for your HI Clinical Center
- Share your story
- Distribute Cards and Posters
- Support Each Other
- Attend the Sugar Soiree
- Share your ideas with us!





Sugar Soirée

SATURDAY NOVEMBER 2, 2019

- IN THE EVENING -

MÜTTER MUSEUM of the College of Physicians of Philadelphia
19 S. 22nd Street, Philadelphia, PA

In support of people living with HYPERINSULINISM



Questions? Please contact info@congenitalhi.org