

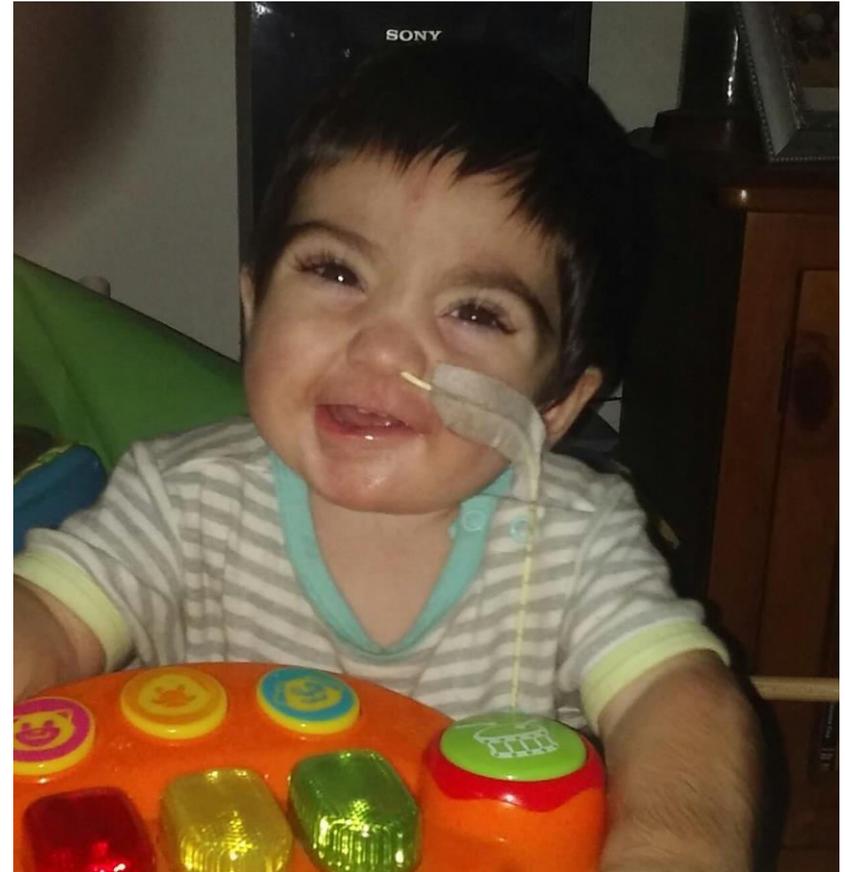
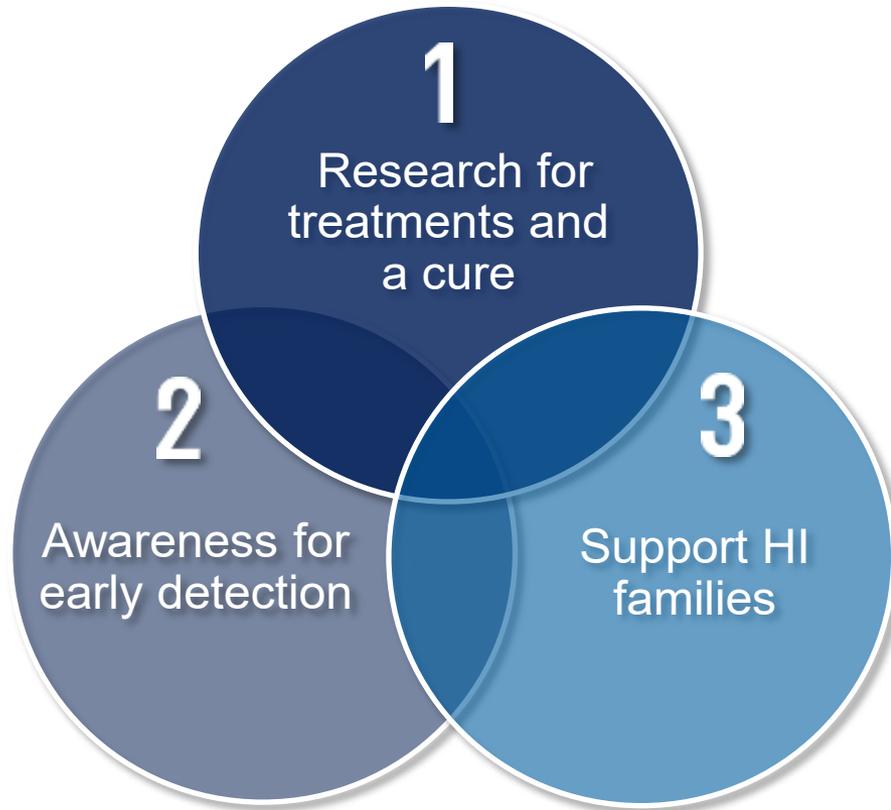


*Congenital Hyperinsulinism
Awareness, Family Support, Research*

Julie Raskin
#CHIFAM2018
September 26, 2018

CHI supports HI research for better treatments and cures,
raises awareness of HI to reduce brain damage and death,
improves access to care and treatment for those with HI,
while providing a community for HI families.





Since 2005 CHI has:

- Secured funding from a private source for a clinical trial of Exendin 9-39.
- Funded research for a pilot study on drug development for a treatment for glutamate dehydrogenase hyperinsulinism with plans for a second grant to be announced this quarter.
- 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:

- Widely shared and advocated for adoption of the PES Hypoglycemia Guidelines.
- Organized 15 HI conferences and meetings around the world bringing together leading global HI specialists to share best practices and research.
- Created the global HI and hypoglycemia awareness poster campaigns to save lives and prevent brain damage.
The posters are available in 14 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 with pharma/biotech/genetic testing companies to help them develop new treatments and products

- CHI has helped patients in dozens of countries around the world receive life-saving medications, treatment and medical supplies. People visit the CHI website from 126 countries.
- CHI has served as the global source of HI patient and family support
- Support from CHI is available in many forms and through many channels. Our support group has over 1,100 people in it and is active 24 hours a day. 3,237 people stay in touch with our Facebook Page. We have 1,265 Twitter followers and 1,069 Instagram followers.
- 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.



Histories

These are the personal journeys that our friends have taken, our HI-stories.



Jackson's Journey



J.R.'s Story



Valentin's Story



Ryan's Story



Asher's Story



Our Social Media Campaigns Raise Awareness



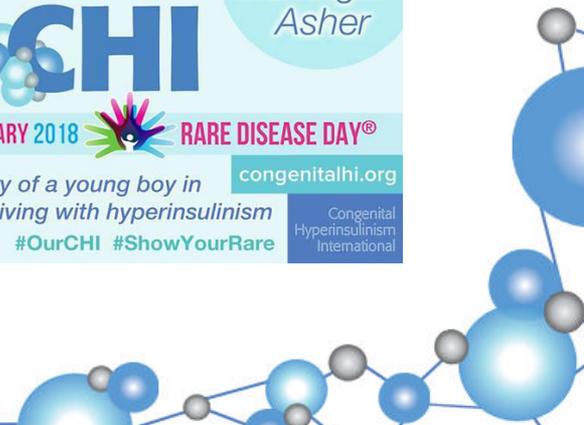
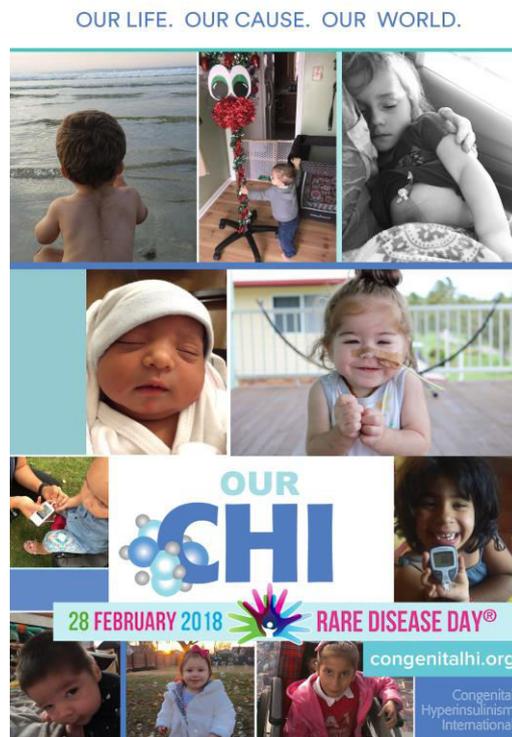
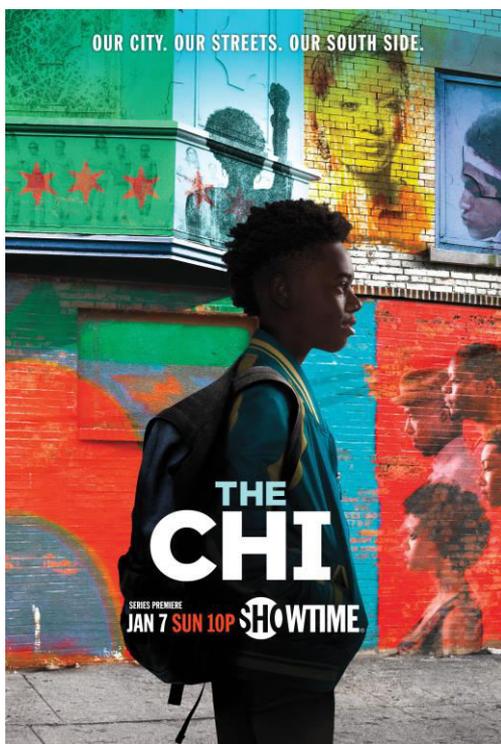
Won'tcha be my sugar?



Won'tcha be my sugar?



2018 CHI RARE DISEASE DAY CAMPAIGN: *creating a new reality out of fiction*



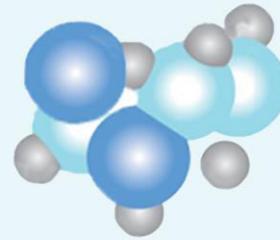
HI stories take many forms

“The world isn't just the way it is. It is how we understand it, no?

And in understanding something, we bring something to it, no?

Doesn't that make life a story?”

-- Yann Martel, *Life of Pi*



SUGARPARENT *quotes*

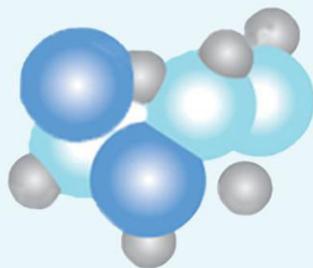
“They told me, ‘He is fine.’

I said, ‘But why is he shaking so much?’

They said, ‘We only check blood sugar for babies of diabetic mothers.’

Four hours later, Noah almost died.”

- Danielle Drachmann



SUGARPARENT *quotes*

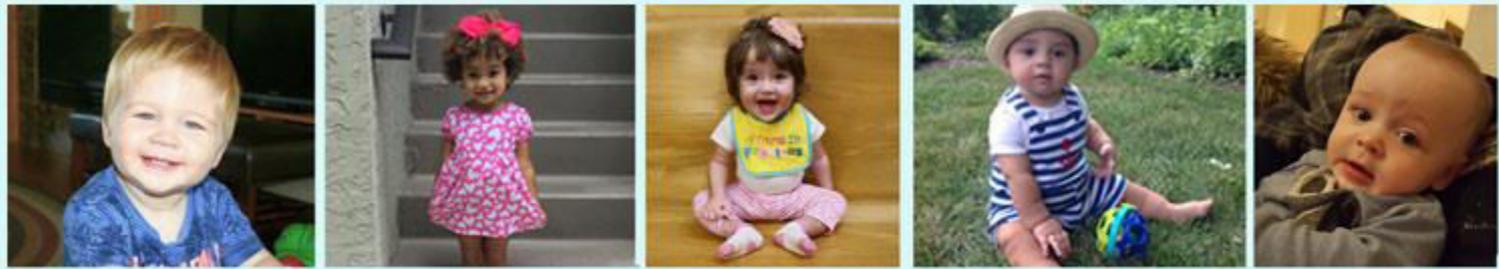
**From her diagnosis, we have
discovered many new words such as**

**hyperinsulinism,
dextrose infusion,
diazoxide,
ocreotide,
pancreatectomy,
gastrostomy,
PET scan...**

**although none of us wanted to
discover them.**

– Cristina Pindado

From Word and Image Stories to Data Stories: The HI Global Registry



Congenital Hyperinsulinism Patient-Powered Research for a Brighter Future



**HI GLOBAL
REGISTRY**

