

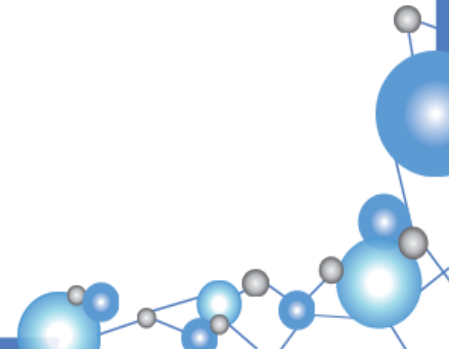


**Congenital Hyperinsulinism International
When Too Little Sugar Hurts, We Help**

**Julie Raskin, CEO
Congenital Hyperinsulinism International
Marriott Hotel in the Hague
The Netherlands
September 22-24**

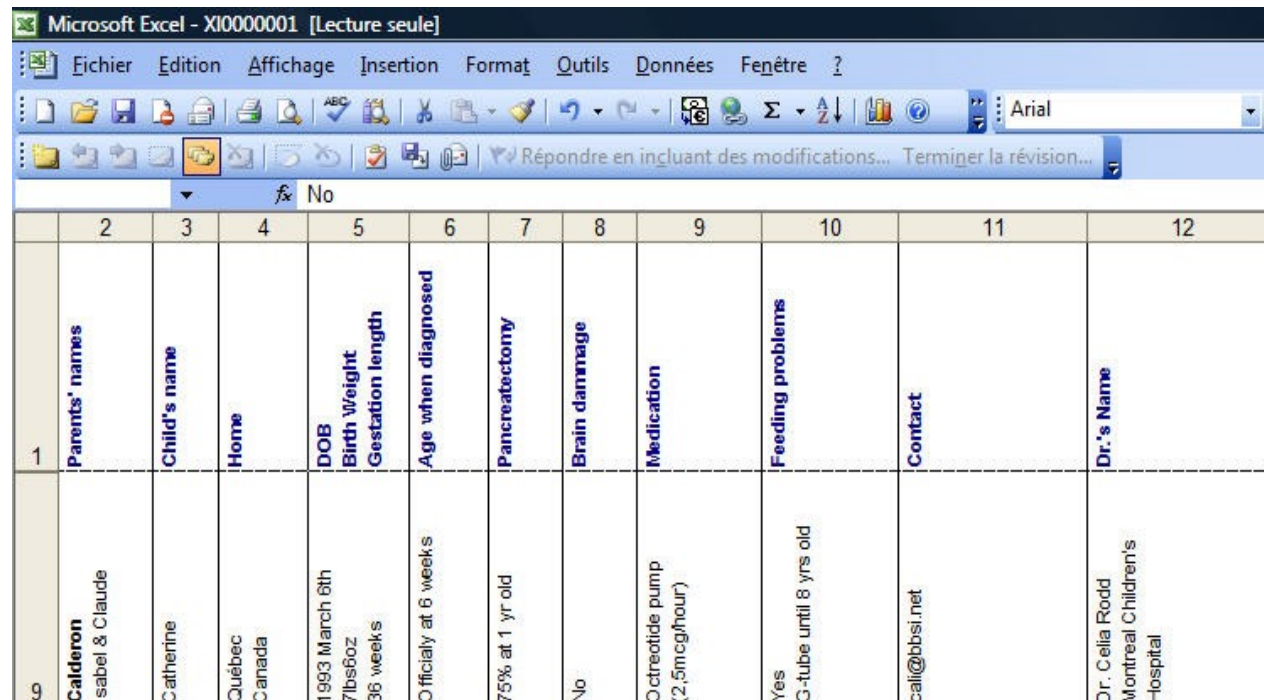


Congenital Hyperinsulinism International (CHI) supports HI research for better treatments and cures, raises awareness of HI to reduce brain damage and death, improves access to care and treatment for those with HI, while providing a community for HI families.



The Origins of CHI

- First HI patient-reported data collection began in 1999
- An outgrowth of our email support group
- We wanted to be able to better remember who was who. This was for ourselves, initially, the members of the group.



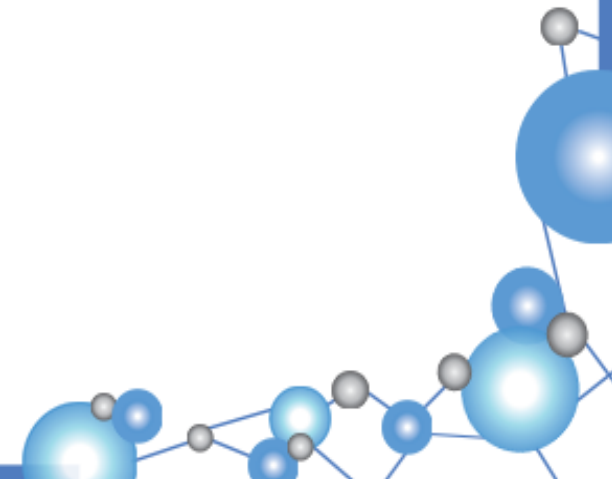
Microsoft Excel - X10000001 [Lecture seule]

Fichier Edition Affichage Insertion Format Outils Données Fenêtre ?

Arial

Répondre en incluant des modifications... Terminer la révision...

	2	3	4	5	6	7	8	9	10	11	12
1	Parents' names	Child's name	Home	DOB Birth weight Gestation length	Age when diagnosed	Pancreatotomy	Brain damage	Medication	Feeding problems	Contact	Dr.'s Name
	Calderon Isabel & Claude	Catherine	Québec Canada	1993 March 6th 7lbs6oz 36 weeks	Officially at 6 weeks	75% at 1 yr old	No	Ocreotide pump (2.5mgcg/hour)	Yes G-tube until 8 yrs old	cali@bbisi.net	Dr. Celia Rodd Montreal Children's Hospital



Since its founding in 2005 CHI:

- Helps patients around the world receive life-saving medications, treatment, and medical supplies.
- Serves as the global source of HI patient and family support available to thousands of people in the HI community around the world with an online support group which is active 24 hours a day.



Since its founding in 2005 CHI:


- Partners with Exeter Clinical Laboratory to provide genetic testing to over **800** patients in **60** countries who are suspected of having HI and who do not have the ability to pay for the testing.
- Designated six CHI Centers of Excellence in the US, UK, and Germany.



Since its founding in 2005 CHI:

- Has created the *Future Without Lows*, *Be My Sugar*, *Stop the Lows*, *HI Never Sleeps* and many other awareness campaigns to save lives and prevent brain damage. Glucose as a Vital Sign coming soon!

Recurrent hypoglycemia in newborns, infants and children is **NOT NORMAL.**



LEARN THE SIGNS & SYMPTOMS OF HYPOGLYCEMIA TO PREVENT BRAIN DAMAGE AND DEATH

CHI Congenital Hyperinsulinism International congenitalhi.org

CHIbras are strong because...



"He went from screaming over every sugar check to telling me, 'It doesn't hurt, mommy,' at just three years old!"

- Kimberly Pfaff

congenitalhi.org

Alexander loves to play soccer, but his mom worries about blood sugar drops when he does.



Learn about HI clinical trials #FutureWithoutLows™

CHI congenitalhi.org

SUGARPARENT QUOTES



"She's our little rock star and fighter - she's been through so much already and always finds a way to keep her smile."

- Janinne Grizzle Cook

congenitalhi.org CHI Congenital Hyperinsulinism International

CELEBRATIONS OF STRENGTH
#SWEETESTCAUSE



Dante is such a special boy who just knows that we must check his blood sugar multiple times a day. He is aware that certain foods are good for his blood sugar and others make his sugar drop. He tells everyone goodbye followed by "I love you with my whole heart." He loves to play with his brother and sister. He is a great student & very analytical. It would not surprise anyone if Dante grows up to be some type of engineer.

SUGAR SOIREE 2019

#STOPTHELOWS!



"With Research, Possibilities Are Limitless."



I support the #SweetestCause because no one should have to fight HI alone!

- Kiersten Smith

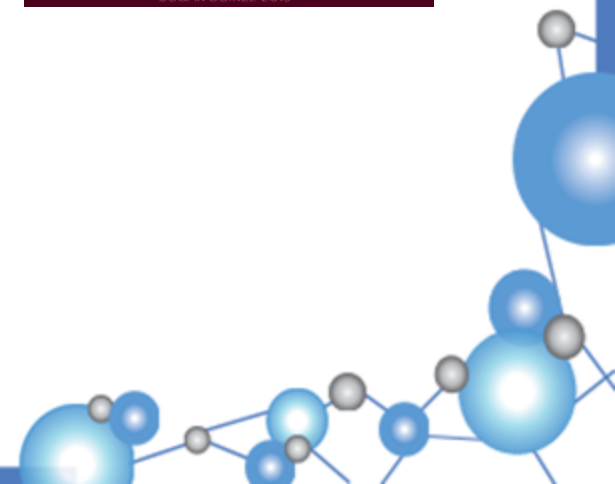
congenitalhi.org CHI Congenital Hyperinsulinism International

I DARE TO DREAM...

that Daphne and the rest of the HI kids in the Philippines will have access to medicine and treatment. We dream that we will no longer have to get medicine and treatment from other countries and not wait for months. Just because HI is a rare disease, our medicines and treatment should not be rare. Our goal is for our country to understand this rare disease and its treatment.

- Faith, Philippines

Rare Disease Day is February 28 | #RareandDaretoDream

Since its founding in 2005 CHI:

- Created and distributed the global HI and hypoglycemia awareness poster campaigns to save lives and prevent brain damage. The posters are available in 24 languages with a 25th on the way.



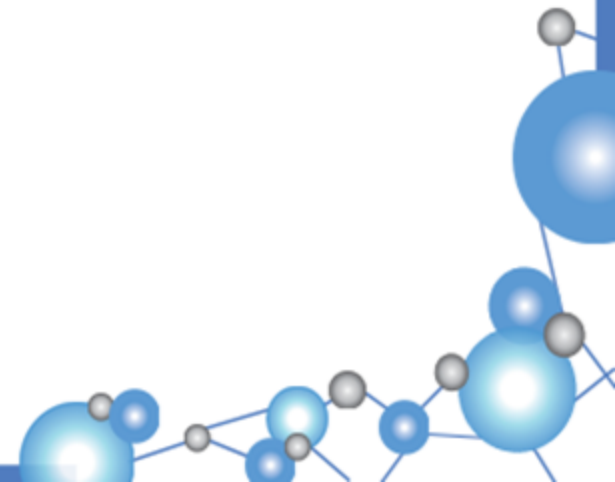
Since its founding in 2005 CHI:

- Has organized 25 HI conferences and meetings around the world bringing together leading global HI specialists to share best practices and research.
- Widely shares and advocates for the adoption of the PES Hypoglycemia Guidelines.
- Informs the patient community of research opportunities



Since its founding in 2005, CHI has:

- Secured funding for 11 pilot research grants for congenital hyperinsulinism.
- Created and manage the HI Global Registry, a key research tool to advance an understanding of the natural history of the condition and new treatments.
- With patient-powered research ensures the patient voice is included in drug development with the hope that new treatments will be developed to help thousands of patients.
- Launched and manages the Collaborative Research Network



CHI CRN Mission and Cornerstones

Create a congenital hyperinsulinism (HI) collaborative research network (CRN) that puts patients at the center of a strategy that leads to faster and more accurate diagnosis, drives new evidence-based treatments and cures, standardizes clinical guidelines, and facilitates increased and improved access.

58 members including physicians, scientists, and patient experts from 18 countries and 5 continents

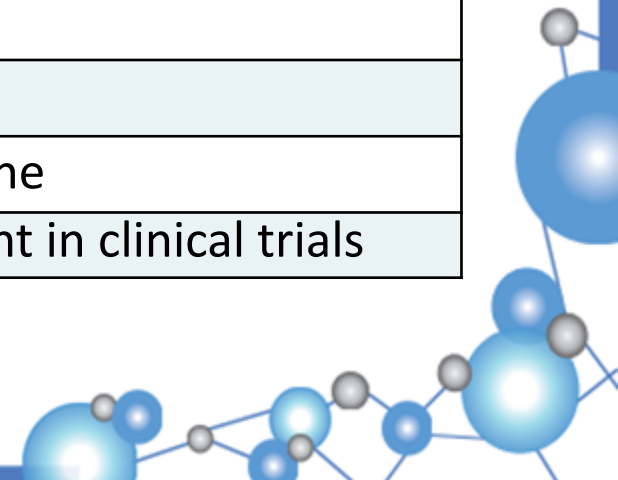
The HI CRN has a commitment to:

- supporting **collaboration** across the globe;
- elevating the **patient voice** and ensuring the patient perspective is central to our work;
- guaranteeing **access** to information, medical specialists, and treatments regardless of income and geography;
- engaging **new researchers and ideas** to find innovative concepts and foster additional leaders in the HI network; and
- **addressing diversity, equity, and inclusion** in our work and our community.



Top 12 Gaps/Needs Prioritized at Lisbon CRN Convening

Workstream	Gap/Need
All	HI Natural History Study
Diagnostics	Identification and adoption of newborn screening approach
Diagnostics	Glucose as a vital sign
Medical and Surgical Treatments	Knowledge of the cause of neurological damage
Care Guidelines & Centers of Excellence	Continually evolving global care guidelines
Clinical Trials & Industry Engagement	An expert group to develop novel clinical trials and outcome measures for regulatory approval
Genetics	Access to genetic testing
Diagnostics	A biomarker for hyperinsulinism
Clinical Trials & Industry Engagement	Meaningful glycemic endpoints
Glucose Monitoring	Device technology for HI patients
Medical and Surgical Treatments	Implementation of personalized medicine
Clinical Trials & Industry Engagement	Expand access and accelerate enrollment in clinical trials

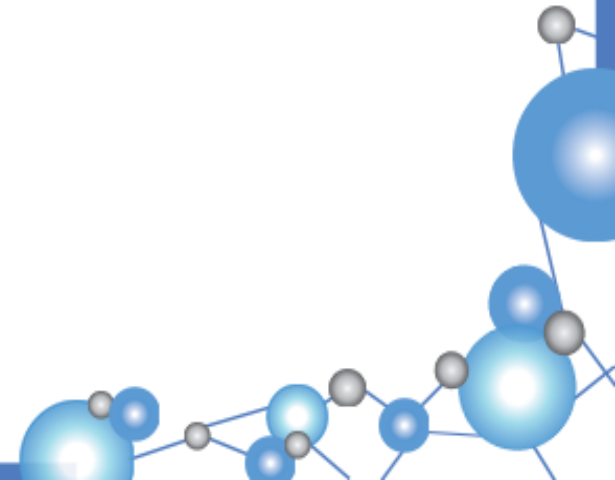


Newborn Universal Screening

Care Guidelines

Glucose as a Vital Sign

Natural History Studies



CHI AT A GLANCE



9 MDBR Grants Totaling
\$700,000+ Funded



503 HIGR Participants
53 Countries
4 Annual Reports



6 Biotechs in pre-clinical or clinical development for new HI treatments



6 Centers of Excellence Designations



58 Experts and Patient Leaders
19 Countries
7 Workstreams



CHI Family Support Forum
2,255 Members
84 Countries



25 International Family Conferences



3 articles published in peer-reviewed journals



9 Sugar Soirées
38 Awards Given



13 Listening Sessions



HI Genetic Testing
786 Children
60 Countries



CHI Website
15,424 Visitors
155 Countries



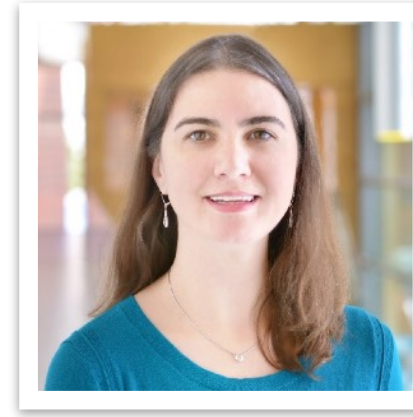
38 virtual HI convenings including conferences, meetings and HI community events



Julie Raskin
Founder and CEO



Jennifer Schmitt
Chief Operating Officer



Tai Pasquini, MPA, PhD
Chief Research Officer



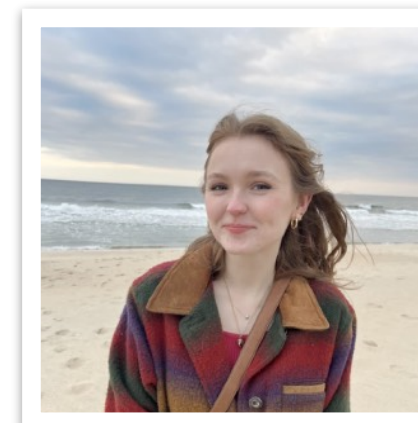
Diane Esty
Development Director



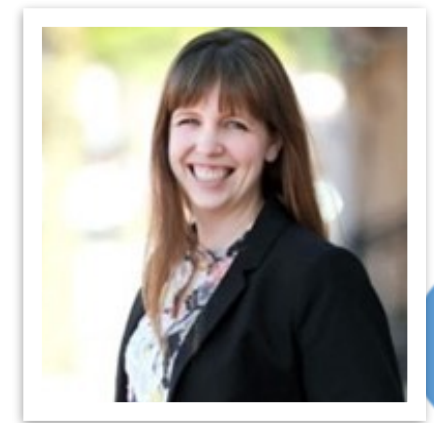
Lauren Lopez, PhD
Registry Director



Mahlet Mesfin
Research and Policy
Associate



Lily Barnett
Communications
Associate



Lora Van Arsdell, PsyD
Research and Support Specialist



