



“From my family story to global advocacy:”

Growing and celebrating the people who live with HI, the professionals who care for them, and the research needed for improved quality of life

Julie Raskin

Ben's mom

Chief Executive Officer

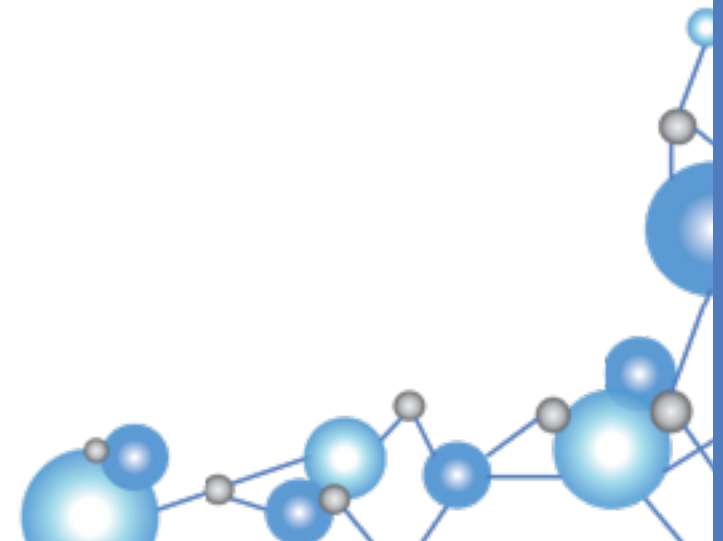
Congenital Hyperinsulinism International

www.congenitalhi.org



Today's Agenda

- **Marveling over KoHHA-DER**
- **Introducing myself and my family's HI journey**
- **Strong Bond with CHOP**
- **CHI Community: From mutual support to a patient advocacy organization**
- **Mission - Research, support, and awareness**
- **All the Places we have Been - The Harvest Moms -
The world of advocates keeps growing!**
- **More on Ben's journey and experiences**
- **Remaining issues that we will all tackle together**



Look at what you have built!

Your success and growth makes me so, so happy,
and I know you will contribute greatly to the global HI
community!



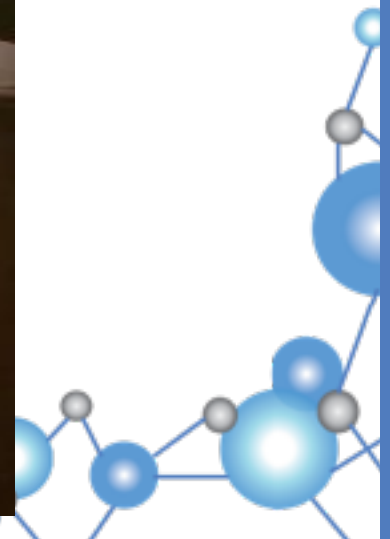
1996 – New Beginnings – we thought!



CHOP is Ben's first home



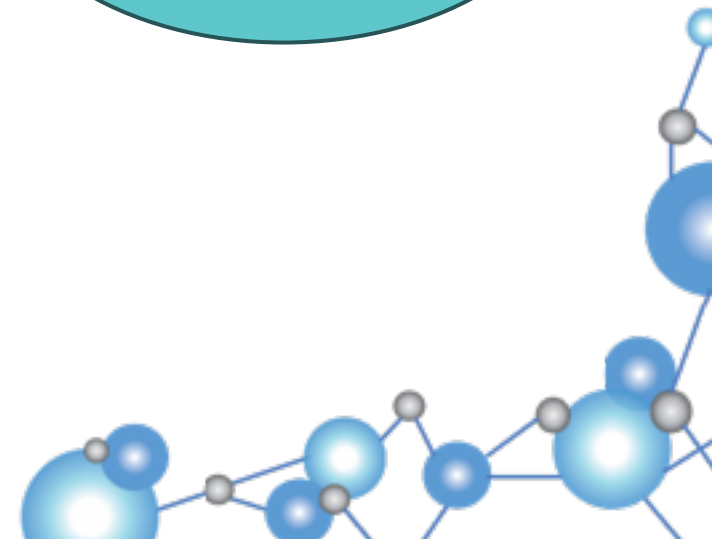
Ben did come home



Our challenges with HI beginning in 1996

- **Late diagnosis**
- **No approved treatment – constant legitimate worry and fear of hypoglycemia**
- **Needed pancreatectomy**
- **Feeding problems**
- **Glucose monitoring laborious and invasive**

Bright spot was
excellent
clinical care at
CHOP



From Personal to community action

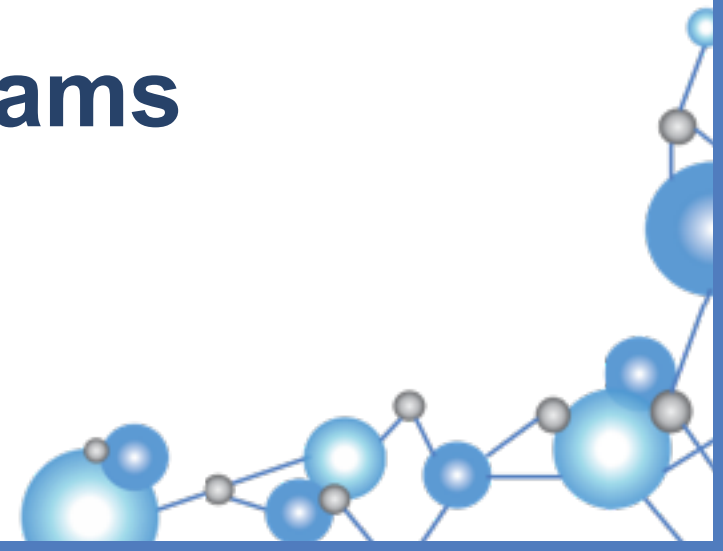
Founded in 2005, CHI supports HI research for better treatments and cures, advocates and raises awareness of HI to reduce brain damage and death, improves access to care and treatment for those with HI, while providing a community for HI families.



Our shared passion!

“For he was a doctor (patient advocate or researcher**), making good what had gone wrong had been his life for half a century.”**

--Time of the Child by Niall Williams



All the Places we have been



Bionic pancreas research at CHOP

2018: Research specific to individuals who have had pancreatectomies for HI



DIABETES CARE



In spite of HI, life can be full & happy

“Getting through college is not a solitary process. It is a process that involves meeting and working with lots of people along the way. Relationships are key to college success. I’m grateful to have met a lot of people who have had a positive impact on my life.

Through them, I have developed a strong love of learning; even learning about learning. Cognition. The bigger picture. The small details. I’m so full of gratitude and grateful to be grateful.”

--Ben Raskin-Gross, 2019



Remaining to solve!

- Cures
- Treatments
- Universal screening and timely diagnosis
- Quality of life
- Tools for homecare like CGM for HI
- Access to existing medications and treatments
- Natural history





Thank you!

