

Dear Friends,

As this very difficult year comes to an end, we thank you and our whole congenital hyperinsulinism (HI) community for all you have done to support those with congenital hyperinsulinism (HI), year after year. The pandemic didn't stop HI from affecting lives, and it hasn't stopped our community from supporting our work. We are so, so grateful to you.

Despite the pandemic, this has been one of the busiest, most productive years on record for Congenital Hyperinsulinism International (CHI). As you know, CHI is the only organization of its kind supporting HI patients in the US and globally. We are celebrating our 15th anniversary this year and there is a lot to celebrate.

15 years ago, there were no new treatments in development for HI. Today there are six biopharmaceutical and biotechnology companies working on new treatments for HI. This is progress! Here are highlights from the past year of our work supporting HI research, awareness, and those living with HI:

- For the years 2020 and 2021, CHI is the recipient of a Rare As One Network grant from the Chan Zuckerberg Initiative to create a hyperinsulinism collaborative research network 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.
- CHI launched the Centers of Excellence (COE) Designation this fall. The CHI COE Program will designate specialist facilities providing the highest quality of care for hyperinsulinism (HI) patients and their families around the world.
- This fall, the HI Global Registry (HIGR), a project of CHI, celebrated its second birthday. HIGR tracks the experiences of those who live with HI, making it possible to quantify and characterize life with HI in a rigorous, scientific fashion to support new research leading to treatments and cures. In our second year of operation, 389 people with HI have registered from 49 countries and every inhabited continent joined HIGR.
- In partnership with the Million Dollar Bike Ride, CHI was able to fund an HI pilot research grant for HI/HA treatments. The researcher, Dr. Thomas Smith, describes his work this way: "Our goal is to target GDH directly to treat all symptoms associated with HI/HA throughout the body."
- Our ongoing genetic testing partnership with the University of Exeter in the UK is going strong. Those suspected of HI from anywhere in the world, who otherwise would not be able to afford it, received genetic testing for HI to determine the type of treatment each baby or child with HI needs. Joining forces with Exeter has enabled 432 individuals with HI from 51 countries to access genetic testing.
- CHI continues to work with aid organizations to help patients in a number of countries access diazoxide, lanreotide, and octreotide.
- CHI hosted two major conferences this year, both held virtually. Over 600 people registered for these conferences from 32 countries.
- We now have information about HI and the signs and symptoms of hypoglycemia available in 21 languages. Our website was visited by people from 135 countries this year.
- CHI has provided patient experience expertise to eight companies developing new treatments.

There is still so much to be done to ensure that new and better treatments are developed and that all babies, children, and adults with HI can access the best possible care and avoid preventable brain damage and other complications. Every step of the way we do this work in partnership with you.

If you are able to, we would be so grateful for an end of year gift to help us improve the lives of HI patients by donating online at <http://congenitalhi.org/donate/> or by using the enclosed form. CHI is a registered 501(c)3 and your donation is 100% tax deductible.

Thank you so much for your continued support.

Sincerely,



Julie Raskin
Executive Director
Congenital Hyperinsulinism International