Congenital Hyperinsulinism International

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Dear Friends,

At the end of another exciting year, we stop and reflect on just how far we've come. Congenital Hyperinsulinism International (CHI) is the only organization of its kind supporting hyperinsulinism (HI) patients in the US and globally. When we founded CHI in 2005, there were no new treatments in development for HI. Those with the most severe form had their pancreas removed because there wasn't a medication to control their HI, but this also caused them a lifetime with diabetes. We needed to change this and to work on improved treatments for all types of HI. We learned from people in the business of developing new treatments that a rare disease community can attract researchers and companies to their space if they:

1) create a united community. ✓ We do this by listening closely and addressing the needs of all in our community.
2) raise awareness of the unmet need. ✓ We do this by sharing our stories constantly and everywhere we can.
3) collect patient reported data. ✓ We do this through the HI Global Registry.

Fourteen years later, there are six biopharmaceutical and biotechnology companies working on new treatments for HI. This is progress! And we have done it all with your support!

Here are highlights from the past year of our work supporting research, awareness and those living with HI:

- This fall, the HI Global Registry (HIGR), a project of CHI, celebrated its first 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 first year of operation, over 300 people with HI from 43 countries and every inhabited continent joined HIGR.
- CHI was able to fund two pilot HI research grants. Thanks to the generosity of the 2017 Sugar Soiree donors, we were able to sponsor a new grant for HIHA research, in addition to the Million Dollar Bike Ride grant.
- We more than doubled the support for the genetic testing partnership project with the University of Exeter in the UK. 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 255 individuals from 39 countries to access genetic testing.
- Access to diazoxide, the only approved medication for HI, is a problem in many countries. CHI partnered to submit a successful application to add diazoxide to the World Health Organization List of Essential Medications, which is a major step forward in our quest to make diazoxide available to all who need it.
- Over 270 people, from fourteen countries, attended the two major HI Family conferences in Philadelphia, PA and Vienna, Austria this September.
- We now have information about HI and the signs and symptoms of hypoglycemia available in 19 languages. Our website was visited by people from 123 countries in the last year.
- CHI advised three biotechnical companies developing new treatments on clinical trial design.

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 to avoid preventable brain damage and other complications. Every step of the way we do this work in partnership with you.

Please 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