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HI GLOBAL REGISTRY 1ST STUDY REPORT NOW AVAILABLE FROM CONGENITAL HYPERINSULINISM INTERNATIONAL

An Early Glimpse at Data, Spring 2019

Glen Ridge, NJ, May 6, 2019– Congenital Hyperinsulinism International (CHI) is very excited to announce the first HIGR study report by the research investigators. In time, the HI Global Registry (HIGR) will generate new insights into congenital hyperinsulinism (HI), drive new research for treatments and cures, and support the success of clinical trials.

“With higher participation over time, HIGR and its published reports will become an increasingly reliable source for the research and clinical communities to better understand the natural history of HI.” – Dr. Davelyn Hood, HIGR Principal Investigator

HIGR is the first global patient-powered congenital hyperinsulinism (HI) patient-reported registry developed for the patient community to share their experiences of living with HI and advancing knowledge and research. It consists of a series of surveys with questions about health, treatment, development, and quality of life. People with HI or their parents or caregivers can participate from anywhere in the world.

Many years in the making, HIGR launched on October 8, 2018. The report includes an introduction to the research project and an early glimpse of data from it. This early glimpse into the high level data collected by HIGR between the date of its launch in October 2018 and mid-February 2019 lays the groundwork for an HI natural history study reported by those who live with the disease.

The early data appears to align with some known features of the disease and its community: (1) the incidence of HI is global, occurring on every continent; (2) HI is not only a disease of the young; (3) there are many types of HI including those from known and unknown genetic causes; and (4) HI occurs together with a number of syndromes.

The foundation for a HI natural history study has been established with the launch of HIGR. As participation grows, the pool of HI data will become increasingly more significant. The investigators intend to initiate an annual reporting process with more complete study data beginning in early 2020.

About the Registry Platform

HIGR data is stored on the secure cloud-based IAMRARE™ Platform which was developed and is hosted by the National Organization for Rare Disorders (NORD). The IAMRARE™ Platform was created with input from patient, caregiver, and government stakeholders to ensure a safe and user - friendly system for study participation. The project is sponsored by Congenital Hyperinsulinism International (CHI) and governed by a group of internationally recognized HI patient advocates and experts, known as the HI Global Registry Steering Committee.

About HI

HI is a life-threatening genetic disorder that causes severe low blood sugar. In most countries the estimated incidence of HI is approximately 1/25,000 to 1/50,000 births. For those with HI the beta cells of the pancreas secrete too much insulin in an unregulated manner. Excess insulin causes hypoglycemia. Prolonged or severe hypoglycemia can cause seizures, permanent brain damage or death, if left untreated. Due to the dangers of hypoglycemia, HI requires timely diagnosis.

About CHI

CHI, a 501(c)3, is a lifeline to those born with congenital hyperinsulinism (HI) and their families. CHI is the global organization dedicated to supporting children and adults born with HI. CHI is a leading source of funding for research for better treatments and cures, and the foremost advocate for increased awareness and better medical protocols for HI to reduce preventable brain damage and death from prolonged hypoglycemia.

For more information about HIGR, please visit www.congenitalhi.org/higlobalregistry or email at info@higlobalregistry.org. You may also contact Jacqueline Kraska, CHI Research and HI Global Registry Program Director, at jkraska@congenitalhi.org or HIGR's Principal Investigator, Davelyn Hood at dhood@congenitalhi.org.