

## **A LightCure on the Horizon: With Congenital Hyperinsulinism International as Advocacy Partner, European Scientists are Developing a Potential New Photodynamic Therapy Treatment for Congenital Hyperinsulinism**

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Glen Ridge, NJ - Congenital Hyperinsulinism International (CHI) is excited to announce a new partnership for the development of a promising investigational treatment for congenital hyperinsulinism (HI). HI is a life-threatening illness with few treatment options; complications include hypoglycemic brain injury with developmental disorders and epilepsy. The LightCure consortium's hypothesis is that light can be used to target and eliminate improperly working pancreatic cells. This project is made possible by a grant of just over €8.2M from European Union research arm Horizon Europe that encompasses CHI's work to strengthen patient engagement and raise worldwide awareness of HI and its myriad challenges.

"If this approach is successful, it would be an incredible breakthrough," says Julie Raskin, CEO of CHI. "We love working side by side with scientists on this important project. By being included, there is a recognition of the important role the patient and caregiver community play in raising awareness of the consequences of late diagnosis and in developing patient-reported outcome measures, which are needed in the treatment development process."

HI is the most frequent cause of severe, persistent hypoglycemia in newborn babies and children, occurring in approximately 1/28,000 births. The focus of the grant is also on advocacy for those with HI. As the second highest-funded LightCure partner at just above €1.4M over 72 months, CHI's role in the project is to create an active patient advisory board to enhance shared therapy decision-making, and to expand the worldwide HI patient registry, for a better understanding of the patient experience. CHI is also tasked with raising awareness of the condition through its Glucose as a Vital Sign campaign, the production of a documentary film and the marshalling of the global HI community to share the consequences of late diagnosis with the medical community. Finally, the grant will fund CHI's work to educate medical professionals on the condition and related clinical research, and to disseminate information about LightCure clinical research opportunities.

The 11-member consortium hopes that by the end of this decade, physicians will have full human use of the photodynamic therapy, which would be applied shortly after birth and tailored for individual patients to best eliminate the side effects of existing treatments. Preclinical testing has produced extremely encouraging results, notes LightCure lead scientist Martin Gotthardt, of Stichting Radboud Universitair Medisch Centrum in the Netherlands. "We can foresee a day when, as a newborn is found to have HI, that baby's quality of life will not be compromised," Gotthardt says. "This development means that within little more than a handful of years, families may no longer have to choose between evils, faced with the replacement of HI with another disease characterized by severe secondary morbidity."

In addition to CHI and Radboud, the participating LightCure organizations are: Erasmus Universitair Medisch Centrum Rotterdam, the Netherlands; Charité Universitätsmedizin Berlin, German; Hochschule fuer Angewandte Wissenschaften, Germany; Medizinische Universitaet Wien, Austria; piCHEM Forschungs- und Entwicklungs GmbH, Austria; TRACER Europe B.V., the Netherlands; Queen Mary University of London, United Kingdom; Great Ormond Street Hospital, United Kingdom; and University College London Hospital, United Kingdom.

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### **About CHI**

CHI, a nonprofit 501(c)3, is a 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 in order to reduce preventable brain damage and death from prolonged hypoglycemia.

### **Contact**

For more information about LightCure, please visit [www.congenitalhi.org/TBD](http://www.congenitalhi.org/TBD). You may also contact Julie Raskin, CHI CEO, at [jraskin@congenitalhi.org](mailto:jraskin@congenitalhi.org) or 973-715-3360.