



## Marc's heart

**The European, Horizon 2020 Project TinyBrains is developing an optical neuroimaging device for assessing brain damage in infants born with severe congenital heart diseases.**

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Every year, about a million babies (50,000 in Europe) are born with congenital heart diseases that can drastically affect their lives.. About 25% of the babies born with those diseases need immediate surgery or other invasive treatment within the first year of life. Over the last decade, the survival of babies born with CHD has increased greatly, with more than 85% of them reaching adulthood. However, about 30% of these children will have neurodevelopmental disabilities, which can range from mild impairments in cognition to severe neurologic deficits. Studies have shown that these neurodevelopment disabilities arise because of ongoing brain injury due to periods of insufficient oxygen delivery to the brain from the fetus' life to early childhood. To change the natural course of the disease, and to prevent brain injury in those infants, an in-depth analysis of the mechanisms of injury combined with innovative technology that seeks to develop new monitoring tools is urgently needed.

Marc was born with hypoplastic left heart syndrome. It is a rare congenital heart disease with no known cause and which occurs during fetal development where the left side of the heart somehow fails to develop normally. Marc's parents, Lola Anton and Chema Cabanillas, were informed about their baby's diagnosis in a regular pregnancy check-up at a middle stage of Lola's pregnancy. This was a life changing moment for the parents, and with the help and continuous support of Sant Joan de Deu's medical clinicians, they decided to carry on with the pregnancy in the hopes for the best.?

A few days before celebrating his first birthday, Marc and his parents, Lola Anton and Chem Cabanillas went to the Sant Joan de Deu Hospital for a follow-up visit and there, we had chance to sit down and converse both with them and with Marc's doctor, the neonatologist Marta Camprubi, clinician at the Hospital Sant Joan de Deu, Barcelona, researchers from th Institut de Recerca Sant Joan de Deu (IRSJD) and partner of the European project TinyBrains We talked about Marc's journey from the moment of the diagnosis until now, the man difficult situations he has gone through and how he is evolving in his first year of life. Th conversations we held with them took us to make a first video of Marc and his heart, to se the basis on why a project like TinyBrains could be an important non-invasive tool for helpin clinicians in pediatric intensive care units.

? The immature newborn brain is very different compared to that of the adult and any inju y that occurs to a baby at early age, most of the times, is irreversible. Therefore, this becom s even more challenging when we are dealing with the vulnerable brain of a premature infan . Thus, as Marta Camprubi highlights, i¿½Being able to understand what is happening wi hin these vulnerable brains, at any given time and why can definitely help us find new strate ies to protect them, and improve their neurological development

### **About TinyBrains**

The European project TinyBrains aims to develop an advanced photonics-based neuro-imaging device for infants like Marc, using a multi-modal approach to understand the mechanisms underlying brain damage in CHD patients. It intends to provide a research platform to improve the understanding of the cellular origin of the brain injury by enabling the assessment of the link between energy demand and oxygen supply. In the long-run, this could help the clinicians reduce the occurrence and the effects of brain injury that these newborns tend to suffer.

### **The consortium ?**

A consortium of six partners will work together for the next four years and includes th following entities: ICFO (Coordinator, Spain) and the University de Picardie Jules Vern (France) as technology developers in academia; the Research Institute of Sant Joan de De and the Sant Joan de Deu Hospital Barcelona (Spain) for pre-clinical and clinical testing; an

HemoPhotonics (Spain), BioPixS (Ireland), and Seenel Imaging (France) as industrial partners



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