



## Institut de Recerca Sant Joan de Deu and ICFO create a joint lab to improve neonatal and paediatric health care

- The new joint laboratory will advance the use and development of photonic technologies to understand, diagnose, monitor and treat paediatric diseases.
- This alliance seeks to provide innovations aimed at improving the quality of life of children with severe pathologies and is made possible thanks to the support of the Joan Ribas Araquistain Foundation, the Cellex Foundation, and the "Torro Solidari RAC1" of Torrons Vicens.

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Neonatal and paediatric health care must adapt to the needs of the most vulnerable patients, especially those with pathologies that have a significant impact on their quality of life.

Improvements in diagnosis, monitoring and treatment are of great importance to increase the likelihood that critically ill paediatric patients will become healthy and independent adults. The ICFO-SJD Laboratory ([jointlab-sjd.icfo.eu](http://jointlab-sjd.icfo.eu)) is a joint project between the Institut de Recerca Sant Joan de Deu (IRSJD) and ICFO, created to accelerate the development and application of photonic technologies to benefit the most vulnerable children. It aims to develop more precise and non-invasive techniques that will help understand their pathologies and apply the most advanced photonic solutions for their care.

Interdisciplinary collaborations play a key role in advancing scientific knowledge. For this reason, the ICFO-SJD Laboratory combines IRSJD's expertise and knowledge in biomedical and clinical research in the care of infants, children and adolescents, with ICFO's experience in the development and management of photonic technologies for health innovation. The alliance has been made possible thanks to the support of the Joan Ribas Araquistain Foundation and "Torro Solidari RAC1" by Torrons Vicens. It brings together the experience accumulated by both institutions over the years with the support of the Cellex Foundation and Obra Social La Caixa, the Catalan Government and the European Commission, among others.

The aim of the ICFO-SJD Laboratory is to face and respond to a wide range of medical challenges, from diagnosis to monitoring and treatment. The motivation of the researchers and the entities that support the initiative is illustrated by the following examples:

#### **From the heart to neurodevelopment**

Every year, 400 children are born in Barcelona with congenital cardiopathies and 40% will need heart surgery during the first year of life. Researchers Dr. Turgut Durduran (ICFO), Dr. Juan Sanchez de Toledo (IRSJD) and Dr. Marta Camprubi (IRSJD) aim to develop tools that will allow continuous monitoring of the brain in these children, enabling the detection of neurological problems and the anticipation of related consequences. A continuous brain-monitoring tool could help medical staff to focus on these patients and protect their neurodevelopment, allowing them to reach adulthood with "normal" neurological development and a good quality of life.

This is the case with Marina, who came into this world prematurely with a severe heart defect. Thanks to advances in the management of congenital cardiopathies, Marina underwent emergency surgery a few hours after birth, and seven days later, underwent open-heart surgery. She was discharged twenty-two days after birth with no apparent developmental growth problems. However, when she began school, her performance was inferior to that of her classmates; Marina was diagnosed with attention deficit hyperactivity disorder (ADHD) and neurodevelopmental problems. Doctors think that her congenital heart disease and subsequent interventions could have affected her normal neuro-development.

#### **Accelerating new therapies**

Collagen-associated muscular dystrophy VI (COL6-RD) is a degenerative muscular disease that mainly affects children, with a major impact on their quality of life as well as life

expectancy. Thanks to the project led by Dr. Pablo Loza (ICFO), Dr. Cecilia Jimenez-Mallebrera (IRSJD) and Dr. Monica Roldan (IRSJD), researchers will be able to advance in new advanced microscopy and image analysis techniques. This will provide precise quantitative methods to control the efficacy of new drugs and therapies as well as accelerate the regulatory process of new treatments, which would subsequently allow the drugs to reach all children in need.

This is the case of Valentino, a child born with an undiagnosed neuromuscular disease. By studying his cells with microscopic techniques, his pathology could be identified as COL6-RD. Beyond identifying his uncertain condition, naming the disease made it possible to follow more closely Valentino's development, to decide on treatment to delay its progression and to improve medical care. Although we can give a name to his disease, there is still no cure for COL6-RD.

#### **Impact of seizures and neuroprotection of the neonatal and infant brain**

Seizures in new-borns and infants are symptoms caused by many diseases. The new-born and infant brain is known to be a vulnerable structure, but the impact of seizures, regardless of their cause, is unknown. Researchers Dr. Turgut Durduran (ICFO) and Dr. Carme Fons (IRSJD) aim to analyse, in a non-invasive way and at the patient's bedside, the relationship between metabolic involvement during seizures and neurodevelopmental disorders. The final objective will be to develop neuroprotection strategies to minimise the future impact of seizures and improve the quality of life and integration into society of the patients.

Marcos was a child who presented seizures within a few hours of his life, up to 100 in one day, and who showed no positive response to antiepileptic treatments until seven days after his birth. The cause of the seizures was a cerebral stroke that left no motor sequelae. However, at the age of two, Marco presented a language delay and autistic behavioural features. The medical team that was monitoring his neurodevelopment wondered if the seizures he experienced during the neonatal period, which were so difficult to control, could be responsible for his neurodevelopmental disorder.

The motivation and aspiration of the IRSJD and ICFO researchers is to assure that their joint work will eventually lead to the best possible outcome for the children involved, allowing them to enjoy a healthy life.

"We firmly believe that joining forces with the IRSJD will lead to significant advances in the application of photonic technologies to improve the quality of life for many of the children who need it most. Putting scientists, technologists and doctors to work together is a key step forward in improving healthcare.", says Dr. Lluís Torner, Director of ICFO.

"The alliance established with ICFO will allow us to continue advancing our knowledge of the serious pathologies on which we are working so that we can tackle complex problems with possible therapeutic solutions" emphasizes Emili Bargallo, Director of the San Juan de Dios Foundation, the entity that manages the IRSJD.

Both Dr. Lluís Torner and Emili Bargallo stress their deep gratitude to the Foundations and



entities that have shown great vision in making this possible.