PAIDHOS

SJD Barcelona
Children's
Hospital's
scientific
and social
publication

2022

SJD Pediatric Cancer Center Barcelona, the leading dedicated pediatric cancer facility in Spain

SJD
Sant Joan de Déu
Barcelona · Children's Hospital

This is a historic time for SJD Barcelona Children's Hospital and, we believe, for childhood cancer too. We opened the SJD Pediatric Cancer Center Barcelona, the leading facility dedicated to pediatric oncology in Spain and second most important in Europe, on the 16th of June of 2022.

The dream we had nurtured for years finally became a reality thanks to the hundreds of thousands of individuals, families, foundations and companies whose donations helped raise the €30M-plus needed to fund the centre. It was also made possible by the work of many of our staff across different disciplines.

This project is a huge responsibility as we must now deliver on what is expected of us and improve the prognosis and quality of life of our brave young patients. We must find new treatments and leverage research and clinical experience to shift the natural history of this group of diseases we call developmental cancer.

Research, clinical practice, training and innovation are fundamental pillars in the Oncology area and our Hospital as a whole. Other specialties that tap these qualities are also featured in this magazine.

The new care model for children with rare diseases and complex chronicity we are rolling out at La Casa de Sofía is a further example covered in this issue, as is Cortex, another pioneering centre, in this case to regulate patients flow, like the control tower of an airport.

This magazine is a publication showcasing some of the major projects we are implementing at our Hospital and which demonstrate that, despite the pandemic, health centres continue to improve services and help make a better world.

Manel del Castillo, Chief Executive
SJD Barcelona Children's Hospital

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Summary

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SJD Pediatric Cancer Center Barcelona, the leading pediatric oncology facility in Spain and second in Europe

The SJD Pediatric Cancer Center Barcelona (PCCB), the leading dedicated pediatric oncology facility in Spain and second largest in Europe, is now a reality. The project kicked off in 2017 with the #ToTheBrave campaign that raised €30M between February 2017 and October 2018 and a further €7M in a second campaign phase to build the new centre thanks to 15 foundation donors, hundreds of businesses and thousands of individuals.

With the opening of the centre in June of 2022, SJD Barcelona Children's Hospital expects to step up its capacity to attend pediatric cancer cases each year from 300 new cases and 105 relapses or second opinion consultations to up to 400 new cases, a rise of 35%. The opening event was presided by the President of the Government of Catalonia, Pere Aragonès, and featured other local and health authorities, patients and representatives from more than 150 companies and organisations whose donations helped make the facility a reality. Among them were the foundation donors that provided over 80% of the funds raised during the campaign: the Leo Messi Foundation, the Barça Foundation, Maria Àngels Recolons Morer, the Stavros Niarchos Foundation, the "la Caixa" Foundation, Esteve, Andbank, Atrys, the Nuevo Milenio Foundation, Asociación Benéfica Anita, Fundació Joan Ribas Araquistain, Rosalia Gispert Barral, Invest for Children, Roman Rosell Dolset and families and patients associations.

"The contribution by donors made the new centre a unique example of social partnership in a project of this type," said SJD Barcelona Children's Hospital chief executive, Manel del Castillo. "This is a strategic project for SJD, which has long been a standard bearer in Spain in the care of childhood cancer and an international reference in the treatment of specific tumours. With the Centre we are expanding on our capacity to treat patients at the first and only dedicated pediatric oncology facility in Spain and the second most important in Europe, at the service of children and adolescents with cancer and their families".

Gloria García, chief fundraising officer at the Hospital, also expressed gratitude towards "all the individuals and organisations whose donations have made the dream of the PCCB come true. "Along with key contributions from companies and entities, over 100,000 individuals collaborated financially in the project through the 200-plus initiatives of all kinds that have left us wonderful stories of solidarity," she said.

New building for a more effective, efficient and fitting way to care for a large number of children

The PCCB is located in a building covering over 14,000 square metres connected to SJD Barcelona Children's Hospital by means of a raised covered gallery and distributed over a total of five floors. Seventy percent of the area is given over to spaces for medical care, while the remaining 30% is dedicated to research and development. Altogether the new facility has 37 individual rooms, 8 transplant chambers, 26 cubicles for the Day Hospital and 21 outpatient consultation rooms. A multidisciplinary team of over 150 staff will be responsible for the Hospital's daily operation.

It also has a Nuclear Medicine and Metabolic Therapy Service, operating theatres, research laboratories and other non-care services such as welcoming common areas with lots of light and space to promote patient and family wellbeing. Indeed, the involvement of patients and their families was fundamental throughout the Centre's design and construction thanks to the Engagement Plan the Hospital put in place at project start.

Proprietary model of pediatric cancer specialisation and care

The new facility represents a milestone in the differentiated treatment of childhood cancer with respect to cancer in adults. Its implementation makes it possible to consolidate the model of research, assistance and care in pediatric oncology developed by SJD Barcelona Children's Hospital for more than 15 years and which is unique in Europe.

The Hospital's approach to pediatric oncology stems from the premise that childhood cancer is associated with the development of the individual in their first years of life, while cancer in adults is related to ageing, so the biology of the diseases is completely different, and drugs designed for adults are of little or no use to children.

"The PCCB staff's specialisation in childhood oncology allows treatments to be modulated according to precision diagnosis, patient age and tumour location, with the aim of minimising the impact of the treatment and its sequelae," said Dr Andrés Morales, Healthcare Director at the facility. "We focus not only on eradicating the disease but fostering best health outcomes for patients and best possible quality of life to give them the chance to fulfil their life goals".

"The PCCB moves the dial on specific research into childhood cancer with new, less aggressive treatments, allows us to train pediatric oncologists (a non-existent specialisation) and lets us care for more children with the disease," said Scientific Director, Dr Jaume Mora. "We apply a translational research model that combines care with research so patients can benefit from the most advanced treatments as soon as possible. It means we can achieve 80% cure rates, similar to those of other centres of excellence around the world, and we aim to reach an even higher survival rate across all the types of pediatric tumours we treat by 2030.

Together with medical specialisation and research, the PCCB also represents a commitment to the specialisation of pediatric on-

Photos from the opening event on 16th of June of 2022. Left to right: Fr Jesús Etayo, Brother Superior of the Sant Joan de Déu Hospital Order; Josep Maria Argimon, Catalan Minister for Health; Pere Aragonès, President of the Government of Catalonia; and Manel del Castillo, Chief Executive of SJD Barcelona Children's Hospital.

The project began in 2017 with the #ToTheBrave campaign that raised €37M from 15 foundation donors, hundreds of businesses and thousands of individuals

The new facility, covering 14,000 square metres, will enable the hospital to boost its capacity to attend new pediatric cancer cases by 35%

The new centre consolidates the pediatric oncology research and care model developed by SJD Barcelona Children's Hospital for over a decade

cology nursing. "Nursing practice in pediatric oncology has evolved in line with progress in treatments and the care provided today is highly complex," said Head of Nursing Anna Negre.

"The PCCB is also the culmination of a career in nursing specialisation. It is a journey we have undertaken with the guidance of science but also targeted at developing skillsets to offer the best care and support to patients and their families."

A dedicated facility open to the world, with a special impact in Latin America

SJD Barcelona Children's Hospital has long been a benchmark in pediatric cancer care in Catalonia and Spain but it has also opened up to the world. This position will be reinforced with the opening of the PCCB as one of the most important dedicated facilities in Europe.

"International collaboration by SJD Barcelona Children's Hospital has had a special focus and impact in Latin America, where inequality between countries and within countries themselves

continues to hamper their health systems' ability to treat childhood cancer," said Dr Guillermo Chantada, Director of the PCCB Outreach Programme. "Our cooperation activity with LatAm institutions and health centres ranges from training to patient treatment, always with the aim of strengthening local capacities."

The collaboration between SJD Barcelona Children's Hospital and Latin America currently involves two major projects that remain active. The Hospital has spearheaded the CLOSER (Childhood Leukaemia: Overcoming Distance between South America and European Regions) project since 2019. This initiative involves European Commission funding and is aimed at bringing the survival rates of leukaemia patients in Latin America into line with European ones.

SJD Barcelona Children's Hospital also created the TELEO (Tele-Education in Pediatric Oncology) programme in 2015. With the support of the Sanofi Espoir Foundation and sponsored by the Leo Messi Foundation, TELEO aims to promote continuing education in pediatric oncology in Latin American hospitals and is currently beginning its second course as a virtual platform.

The opening of the PCCB is a new impetus for the work and development of intercontinental partnerships, coinciding this year with the International Society of Pediatric Oncology congress hold in Barcelona from 28th of September to 1st of October of 2022.

International cooperation programme for children with cancer resourceless

Parallel to the Centre project, SJD Barcelona Children's Hospital also has the PCCB Charity Fund, an international cooperation programme for disadvantaged children with cancer living in countries where they cannot access the treatment they need. The aim is to facilitate treatment to these patients with certain kinds of childhood cancer referred by their oncologists in their home country.

The PCCB Charity Fund is possible thanks to the solidarity of foundation, business and individual donors connected to the PCCB. And since resources are limited, the number of children treated every year changes according to the donations received. ■

The PCCB will make it possible to boost pediatric oncology training and partnerships with health centres and institutions from other countries and continents, with a special impact in Latin America

The Brain of the Hospital

SJD Barcelona Children's Hospital is the first facility in Spain with a control centre to regulate patients flow and improve Hospital management. The staff leverage screens to make a real-time assessment of key data on Hospital performance to improve decision-making.

It looks like an airport control tower but in a hospital ward. Several large screens command the room, displaying real-time information on how many patients are currently being operated on in the theatres or will be admitted to ICU in the next few hours, transferred from intensive care to a room, are admitted on each ward and other information of strategic importance to Hospital operation.

With this real-time overview of what is happening in the Hospital at all times, staff can take the best decisions regarding optimal bed and resource management to prevent overcrowding and bottlenecks.

"Technology-driven environments like this can be hugely useful at times like the peak of the pandemic but also for other types of health emergencies," said Dr Francesc García Cuyás from the Medical Directorate of the SJD Barcelona Children's Hospital. "Having all information in real time enables instant insights into ICU bed status, COVID emergencies and PCR test-result waiting times, greatly streamlining management and powering decision-making so we can start to get ahead of the curve in some areas," he said.

The area, named Cortex, includes not only the command centre but a patient monitoring system (Ecare) and contact centre for patients and their families.

Remote patient monitoring

With Ecare, staff can remotely monitor hospitalised children who need to be followed at all times wherever they are: in their room, walking around the lobby or playing in the games room. This initiative has made it possible, for example, for babies with heart problems who previously had to be kept under observation in the ICU following surgery to be transferred to a room with their mother, with a small connected device analysing their clinical progress at all times and alerting staff if their condition deteriorates.

The team at the Hospital is now working to be able to detect these complications earlier and even prevent them. Data from each patient will be compared against hundreds of other cases using artificial intelligence to generate new insights into the disease and predict potential complications in advance.

Ecare activity in the first six months of operation focused on patients admitted to the Hospital with cardiological problems who were monitored using the system. A preliminary assessment revealed that, in addition to improving the patient/family experience as the monitoring system enabled greater mobility around the Hospital, it also slightly reduced their stay in the ICU and on the ward.

In the next few months the centre intends to expand the initiative to hospitalised cardiology patients at home and broaden it to patients with other conditions.

This paradigm shift in cardiology patient care is made possible by the support of the Daniel Bravo Andreu Private Foundation within the framework of collaboration between this philanthropic organisation and SJD Barcelona Children's Hospital, that has made the Heart Area a benchmark in highly complex pediatric cardiology internationally.

Multi-channel communication space with patients

Cortex also has a multi-channel communication area with patients' families called the Contact Center. This is a space where staff remotely visit patients not requiring face-to-face care and answer healthcare queries from families. The medical team visits them over the phone and by videoconference and resolves queries by phone, internet or any other channel. 46% of visits at the Hospital are non-face-to-face today.

The Contact Center is now being expanded with different staff profiles to respond to patients who reach out to it via remote channels and require an answer to a care or administrative matter. ■

SJD Barcelona Children's Hospital features a control centre unique in Spain that provides staff with a real-time overview of Hospital operation

The space also has a system for remote patient monitoring and a contact service for patients and their families

New Neonatal ICU: divided into rooms for parents to spend 24 hours with their baby

SJD Barcelona Children's Hospital is the first hospital in Catalonia with a Neonatal Intensive Care Unit that walks back from the traditional open-space model in favour of a space divided into single family rooms. Scientific evidence shows that this new model facilitates closer family involvement in caring for baby and improves infant wellbeing.

The structure of the new ICU allows parents to spend more time with their baby and encourages breastfeeding

"The fact that parents can spend as much time as possible with their baby is important for all infants, but fundamental in the case of premature babies since it encourages breastfeeding, allowing more skin-to-skin contact. For these children, contact with the family is part of the treatment," said Neonatal ICU head Dr Martín Iriondo and nursing coordinator, Maria José Troyano.

Around 600 babies are admitted to the SJD Barcelona Children's Hospital neonatal ICU each year. These are infants who were born in the Hospital or referred from other centres because they were born prematurely or presented health problems such as congenital malformations, respiratory syndromes or infections, among others.

The environmental conditions of the space where they spend the first days of their lives play a very important role in their wellbeing and progress. A study published in The Lancet shows that an ICU divided into rooms, compared to a conventional open space plan, brings many benefits. It not only guarantees greater privacy and comfort for the family but encourages breastfeeding, since baby can be fed directly and the kangaroo (skin-to-skin) method used for longer so mothers can spend more time with their children. It also better controls noise and light, favouring sleep for newborns and their neurological development, especially in the case of preterms. The new structure encourages greater family involvement in caring for their baby.

Space for families

The new NICU the Hospital opened a few months ago, with an area of 2,266 square metres, is four times larger than the previous one. It features 44 beds (6 more than the old unit), distributed into 24 single rooms, 5 doubles, 2 triples and one quadruple; a family room fitted with a kitchenette/office, relaxation area with sofas and a TV, a bathroom with a shower, a nursing area, two staff work areas and a box to run simulations.

Operations within the unit

Two of the individual rooms and one of the double rooms can be converted into theatres to operate on the most unstable babies without having to transfer them outside the unit and two beds are specially equipped for performing ECMO (extracorporeal life support, indicated when breathing or circulation fails). Congenital diaphragmatic hernias, necrotising enterocolitis, premature babies with retinopathy, ductus and some digestive malformations, among others, are operated on in the NICU. Each year, the Hospital performs around 110 neonatal surgeries of which a fifth can be performed in the NICU itself.

The new unit incorporates the latest technologies and features four levels of patient monitoring, allowing staff to detect an alarm signal quickly, wherever they are, as it is sent instantly to four devices: a monitor inside the box, another outside, one at the nursing control station and another to the mobile device the nurses carry in their pocket at all times. There is also a system enabling safe drug management and software that optimises resource management.

A space simulated prior to construction

The new Neonatal Intensive Care Unit at SJD Barcelona Children's Hospital onboards all these measures as well as others suggested by patients' families. During the NICU design process, the project leaders invited a group of families who had used the service to express their needs and make suggestions on what the new space should include.

In addition, to test the spaces before building the unit, a life-sized cardboard model of an individual room was made to allow staff to simulate different common care practices in a neonatal unit such as stabilising the patient, CPR, and urgent and complex procedures like ECMO and surgery. The aim was to check that the dimensions were suitable and the distribution of space and furniture adequate, and to introduce these improvements into the plan before it was materialised. ■

Parental contact is fundamental for premature babies and is part of the treatment they need

Mediterranean diet and mindfulness during pregnancy cut risks of low weight babies by up to a third

Researchers from BCNatal (SJD Barcelona Children's Hospital and Hospital Clínic-IDIBAPS), with the support of the "La Caixa" Foundation, have shown for the first time that actions based on the Mediterranean diet and mindfulness to lower stress in pregnancy can reduce the frequency of low birthweight and other pregnancy complications.

> "Low birthweight due to fetal growth restriction occurs in 10% of pregnancies"

Low birthweight caused by fetal growth restriction occurs in around 10% of pregnancies and 30% of high risk pregnancies. No effective treatment was known until now. A study published in the journal JAMA, led by researchers from BCNatal (SJD Barcelona Children's Hospital and Hospital Clínic-IDIBAPS) and the University of Barcelona, with the support of the "La Caixa" Foundation, has shown for the first time that fetal growth can be positively impacted by maternal lifestyle changes. The study specifically demonstrated a reduction in low birthweight babies of between 29% and 36% by intervening in the mother's diet and lowering her stress level.

Low birthweight is associated with health problems as an adult

Low birthweight babies (birthweight below the 10th percentile) account for 10% of all births and 30% in the case of a high-risk pregnancy. Low birthweight reflects growth restriction in fetal life and is recognised by the WHO as one of the leading causes of perinatal mortality worldwide. It is also associated with poorer neurodevelopment in childhood and more metabolic and cardiovascular health problems as an adult. Until now there was no treatment to prevent or improve low birthweight.

The research team led by Eduard Gratacós, director of BCNatal and the Fetal and Perinatal Medicine group at IDIBAPS and CIBERER, has been studying the possible causes and consequences of low birthweight for many years. "We saw that mothers of low birthweight babies often had a suboptimal diet and high stress levels," Dr Gratacós said.

This led to the idea of conducting a clinical trial into whether structured interventions based on the Mediterranean diet or stress reduction could moderate foetal growth restriction and other pregnancy complications.

Image of the presentation of the IMPACT study with Eduard Gratacós in the foreground

IMPACT BCN: a study to intervene in maternal lifestyles

The three-year IMPACT BCN study involved more than 1,200 pregnant women at high risk of having a small baby at birth. Pregnant women were randomly divided into three groups: one had visits with a nutritionist to follow a Mediterranean diet; a second followed a mindfulness programme to reduce stress; and a control group underwent standard monitoring. The groups were followed up to see how their babies were developing and whether there were any complications during pregnancy and childbirth.

The dietary intervention was based on methods used in the PREDIMED study that had demonstrated the benefits of the Mediterranean diet in preventing cardiovascular disease and was endorsed by the American Heart Association (AHA). The women in this group had a monthly visit with a nutritionist to change their dietary patterns and pivot them to a Mediterranean diet, adding more fruit and vegetables, white meat, oily fish, dairy products and whole wheat grains. They were also given products high in omega-3 and polyphenols for free, i.e., extra virgin olive oil and walnuts. “We measured biomarkers in blood and urine related to the intake of walnuts and olive oil to objectively assess whether they were adhering to the intervention,” said Francesca Crovetto, physician and postdoctoral researcher from the Mother and Baby Medicine Service at SJD Barcelona Children’s Hospital.

The stress reduction intervention was based on the Mindfulness-Based Stress Reduction (MBSR) programme developed by the University of Massachusetts and adapted to pregnancy by the Barcelona researchers. Groups of 20-25 women were formed to follow the pregnancy-adapted programme for eight weeks. “Questionnaires were completed at programme start and end and levels of stress-related hormones, cortisol and cortisone measured to identify whether any stress reduction had occurred,” Dr Crovetto said.

The study showed for the first time that a structured and guided Mediterranean diet or mindfulness during pregnancy reduces low foetal weight percentages and pregnancy complications such as preeclampsia and perinatal death. The results were clear: pregnant women in the control group had 21.9% low-birthweight babies, a percentage that was significantly reduced in the Mediterranean diet (14%) and mindfulness (15.6%) groups.

“This is groundbreaking research, as it shows for the first time that a structured lifestyle intervention reduces complications in pregnancy for which no previous treatment had shown positive effects,” said Dr Gratacós. ■

“Low birthweight is associated with poorer neurodevelopment in babies”

“Following a Mediterranean diet in pregnancy and not being stressed reduce the risk of having a low-weight baby”

La Casa de Sofía: first facility for children with a rare disease and complex chronicity in Spain

La Casa de Sofía is targeted at the pediatric population with complex chronicity and/or advanced disease with the aim of preventing their hospitalisation or delaying it as long as possible. The centre offers children a safe and friendly setting where expert staff provide the care the children need and train families in continuing with it when they go home. The project was made possible thanks to a partnership between CatSalut, SJD Barcelona Children's Hospital, Hospital Vall d'Hebron and the Consorci Corporació Sanitària Parc Taulí.

SJD Barcelona Children's Hospital has opened La Casa de Sofía, the first care centre for children with complex chronicity or advanced disease in Spain. The facility is sponsored by CatSalut and its Social and Healthcare Master Plan and was developed by SJD Barcelona Children's Hospital in collaboration with Hospital Vall d'Hebron and the Consorci Corporació Sanitària Parc Taulí.

The main objective of this intermediate care centre is to avoid unnecessary admission to acute care hospitals, delaying possible long-term hospitalisation as long as can be by means of a clinical and organisational approach that delivers clinical stability and the functional improvement needed. It has also been designed for post-hospitalisation purposes, using planning and support at discharge to avoid further risk of hospitalisation so patients can go home with optimal functionality and support.

La Casa de Sofía is among the first centres of its kind in Europe and aims to become a benchmark in Catalonia for helping children with complex care and palliative care needs.

"La Casa de Sofía aims to become a specialised facility offering more suitable care than conventional hospitalisation of children with severe chronic diseases and their families," said Dr Sergi Navarro, head of the Department of Palliative Care and Complex Chronic Patients at SJD Barcelona Children's Hospital.

Rocío Escobar, the centre's nursing coordinator, said: "Besides assisting families in the practical part of learning how to take care of their children, we support them in coming to terms with diagnoses and the changes that occur in their clinical progress".

The backstory to La Casa de Sofía and its purpose

The new centre is called La Casa de Sofía because one of its sponsors is Jordi Cruz, the father of Sofía, a child who was unable to overcome a rare disease. It is precisely patients with these conditions who are the main users of the facility, since many of them present progressive disease evolution and multi-organ involvement leading to a complex and chronic or advanced situation.

Jordi Cruz believes La Casa de Sofía will be a qualitative leap in the care provided to the families of children with rare diseases. "Now they will have a place where their children can receive the care they need in a home-like setting and where the parents can also begin to prepare for when the time comes to go home".

A pioneering facility

Until now there had been no intermediate care centre for pediatric chronicity in the health sector. It is estimated there could be around 3,000 children with advanced disease in Catalonia and a similar number with a complex chronic condition who could benefit from this type of facility at some point in their clinical progress. In fact, CatSalut's most recent Strategic Plan had already established the need to do more in the area of chronic pediatric diseases and the implementation of La Casa de Sofía is a significant milestone in moving towards this goal.

The centre will look after children from all over Catalonia. Most patients will come from the three major hospitals that work in chronic pediatric diseases and palliative care: Vall d'Hebron, Parc Taulí and SJD Barcelona Children's Hospital. The envisaged care programmes include physiotherapy and multi-sensory therapy, as well as creative activities and bereavement support workshops to train caregivers and relatives.

Currently in its first stage, the facility covers an area of 1,274 square metres, including a 260 square metre garden. It boasts 15 rooms, a space for families, a kitchen and a games room, in addition to staff areas.

La Casa de Sofía is part of a broader project called Red Únicas, sponsored by SJD Barcelona Children's Hospital and involving the participation of 25 large hospitals from across Spain's regions. The aim is to ensure comprehensive care for pediatric patients with rare diseases. Its future development depends on obtaining European funding. ■

La Casa de Sofía is part of a broader project called Red Únicas, involving the participation of 25 hospitals

SOM Mental Health 360, a Pioneering Digital Platform

SOM Mental Health 360 is a pioneering digital platform that aims to inform, support, empower and raise awareness in society around the importance of mental health. The portal responds to the rise in demand for accurate information and meaningful services during the pandemic, when people aged 18 to 34 presented depression rates of over 15%, half as much again as the over-50 population.

The impact of lockdown was greater on people aged 18 to 34, who presented depression rates of over 15%, half as much as the over-50 population.

According to a study carried out by researchers at the Sant Joan de Déu Health Park, the likelihood of a person living alone developing depression is five times higher than someone not living alone.

The COVID-19 pandemic only made things worse. Another study by the same SJD centre found that people aged 18 to 34 were the most affected by the impact of lockdown. The data show that young people presented higher rates of anxiety and depression than the middle-aged and elderly population.

“The population with the highest rates of depression and anxiety is among over-50-year-olds. However, it appears that young people were more vulnerable during the pandemic, possibly because their relationship needs are different. They require face-to-face contact and more varied than other population groups. The fact that they took a bigger hit in areas like job losses and reduced spending power may also have influenced the findings,” said Dr Joan Domènech, researcher and study lead.

The study concluded that loneliness is a predictor of depression and anxiety and is also the leading cause of depression among modifiable risk factors, above other conditioning factors like socioeconomic variables and healthy habits. In fact, people with financial problems are also at a significant risk of depression, with a probability 3.5 higher than people without this problem.

Dr Josep Maria Haro, director of Teaching, Research and Innovation at Sant Joan de Déu Health Park, says that although loneliness is a triggering risk factor for depression it is a variable that can be modulated.

“In other words, if we act to correct it, the person’s situation will improve,” he said.

Internet searches on mental health up 600%

After nearly two years of a pandemic and months of lockdown, mental health disorders have multiplied, and Internet searches have shot up by 600%.

This has accentuated the need for proven and reliable information online information regarding mental health-related issues.

SOM Mental Health 360

With this background, SJD Barcelona Children’s Hospital presents SOM Mental Health 360, a digital platform based on co-creation by people with a mental disorder, families, health professionals, the social sector and education area and the general population which aims to inform, support, empower and raise society's awareness around the importance of caring for people's mental health.

The pioneering initiative, which initially began before the pandemic, is spearheaded by different centres that attend people with mental health problems from the Sant Joan de Déu Hospital Order to respond to this demand.

A platform with an inclusive and co-creator vocation

The SOM Mental Health 360 portal onboards updated content in the field of mental health and is progressively expanding the diversity of its formats. The aim is to craft a smart platform that provides content pivoted to each person's preferences and produces a best-in-class user experience. Users are also the principal platform prescribers, making it a reliable and safe source of information for anyone requiring information they can trust on mental health.

Digital meetings, consultations with an expert and testimonies from health professionals, people with a mental disorder, family members, educators and associations are currently provided, along with outreach and specialised articles, among others. All platform information is checked by a multidisciplinary scientific committee to ensure veracity of information.

"We want it to be a sustainable content and services platform that delivers know-how and engages professionals from other centres," said Eduard Serrano, coordinator of the Eating Disorders Service at SJD Barcelona Children's Hospital and member of the SOM Mental Health 360 technical and scientific committee. "That is why over 39% of the professionals are from outside SJD, as diversity makes us stronger. "People are at the heart of our health and social care and are entitled to accurate, proven information that allows them to make decisions regarding their health and emotional wellness," he added.

The aim of the platform is to support people throughout their lives, from childhood to later life, with special care given to the transitions between the different periods. "There's no point starting a project for the public without involving the public, is the way we look at it. We know people are keen to talk and express their concerns about mental health issues without stigmatisation. That is why we want SOM Mental Health 360 to be an interactive and intelligent space that everyone can contribute to and use," said Cristina Molina, director of Mental Health Analysis and Strategy at the Sant Joan de Déu Hospital Order in Catalonia.

Home-based care programmes

The Mental Health Area at SJD Barcelona Children's Hospital has also implemented two home-based care programmes for children and adolescents with eating disorders and people presenting especially complex mental health crises.

With this initiative, the staff is keen to provide a very intense,

experience-driven response to serious mental health cases, helping stop the child or young adult from withdrawing from their environment and getting their life back on track as quickly as they are able to. Two multidisciplinary teams comprising psychiatrists, clinical psychologists, nurses, social workers and social educators are running these new programmes that supplement already existing ones that have been implemented at SJD for a number of years. ■

The SOM Mental Health 360 platform is based on co-creation with associations of relatives and people with first-hand experience in mental health

The platform has delivered encouraging results in its first year of operation, with 77,000 users and 120,000 visits to the website.

INTERVIEW: RAFAEL ARTUCH | Head of the Biochemistry Laboratory at SJD Barcelona Children's Hospital

"Advances in gene technology and biochemistry enable diagnoses in weeks that used to take years"

Rafael Artuch is a physician and specialist in clinical biochemistry and has been the head of the CIBERER U703 group since 2007. Dr Artuch heads up the Hereditary Metabolic Diseases Laboratory at SJD Barcelona Children's Hospital, tasked with determining multiple biological parameters that yield information on the diagnosis and monitoring of metabolic diseases. He has been the assistant scientific director of the Sant Joan de Déu Research Institute for the past seven years.

Could you explain your duties at the Hospital?

From the care perspective, which is the main part of my job, I am a specialist in clinical biochemistry. I am currently the head of the Biochemistry Laboratory in the hospital's Laboratory Area, where we run specialist tests that are more comprehensive than routine bloodwork since we are talking about a specialist pediatric hospital and which focus particularly on the area of rare metabolic diseases.

What are congenital metabolic diseases?

Also known as inborn errors of metabolism, they are diseases that arise from a genetic alteration -specifically a protein or enzyme- blocking a particular metabolic process. This blockage alters the normal function of a number of cells and organs and manifests in a series of particular symptoms in each patient, such as those associated with different types of neurological syndromes.

Could you explain the research part of your work?

The research part includes leading projects and writing ar-

ticles. I am also part of the CIBERER network, the reference organisation in Spain in research into rare diseases comprising 57 research groups linked to the 29 institutions behind the consortium. I currently run the Metabolic and Mitochondrial Medicine Programme.

How has the laboratory evolved to date?

I have been part of the lab team for 22 years, having joined in the year 2000. Back then there was just the director of the lab and myself, when I was doing my residency.

There was just one team and two assistant teams and we gradually developed different techniques. We later won a research project that allowed us to onboard new technology and expand the team. At the start there were only three or four of us and we grew into the eight-person team we are now: four technicians and four physicians. We also have a researcher contracted by CIBERER to support us in the genetic studies.

There must have been major changes at the technological level too, right?

Yes, without a doubt. We have gradually swapped out the 10 or 12 pieces of equipment we had for new-generation techniques, particularly mass spectrometry connected to different systems that allows us to perform highly targeted and precise analyses in a short time. These techniques are complicated to understand and use. That is why it is so important to have highly specialised staff on the team who master these work procedures.

In what ways is the Hospital laboratory a benchmark? Since we have equipment here in the Hospital laboratory for very specific and specialised techniques that are only performed in one or two hospitals in Spain at the most, we have generated a series of medical services that are highly sought after by other hospitals both nationally and abroad who ask us to analyse neurotransmitters in cerebrospinal fluid samples, for example. Because we have specialised in neurometabolic disorders over time, in the past 15 years we have analysed some 6,000 samples of cerebrospinal fluid from children from around the world.

What is your work protocol to diagnose rare diseases?

The traditional work framework in terms of a specific known disease followed this protocol: when we received a patient diagnosed with a rare disease we ran metabolic tests that guided us towards one gene or another, and when we had localised these markers we then had to pick through one by one to find what could be affected. This was obviously no mean feat

“There are approximately 1,000 rare metabolic diseases”

“In the past 15 years the Hospital laboratory has analysed 6,000 samples of cerebrospinal fluid from children from around the world”

since there are some areas of the metabolism that depend on only two genes but others that are determined by 200. Depending on the area involved, a diagnosis could take four or five years. Today, fortunately, when we find a metabolic clue, the genetics team can sequence 6,000 genes at once and get a diagnosis in a week or two.

What do you do in the case of a disease that is not yet known?

The cost of genetic studies has fallen substantially in recent years so it is increasingly common for geneticists to raise questions as they work with patients with a particular condition, such as an epileptic disorder, and when they study it they realise the patient might also have a gene mutation affecting their metabolism. The laboratory later has to confirm or reject this.

Can you also identify new genes in the lab?

Because genetics has evolved so much in the past five years, studies today have the possibility of sequencing not just five or six thousand genes but the 25,000 we have in total. All these genes may be known to us or not. I mean, we can know whether they are behind a particular disease or not. In this third scenario, the periods are much longer and it is very important to also have other research groups performing different functions. When we find a new gene, even if we identify that the problem has a metabolic basis it is not as simple as showing the cause of the disease. We sometimes need to develop animal models at the same time that show that this specific gene is the cause, for example, of a brain disease.

How does the family react in this case?

Often when we identify a new gene that may be causing the disease the family can, quite rightly, request genetic counselling. Of course when we give them an answer we have to be absolutely certain that the gene in question is the one causing the condition. Identifying a new gene is a key moment for the entire team of 25 or 30 people who have worked intensely to identify a disease that may only affect three children in the whole of Spain. In terms of general medicine, that might be hard to understand, but that’s the story with rare diseases. So it is true that these diseases are not well recognised and are often much more neglected in comparison with more widespread conditions, but we should highlight the fact that there are many people involved in the process of researching a rare disease.

What are the strategic areas being considered for the future?

We have two strategic areas. One is biomedicine and the other, technology. Regarding biomedical research, our contribution involves identifying the bases of diseases, which in our main action area are hereditary metabolic diseases. This group of conditions comprises between 600 and 1,000 diseases in which there are genetic disorders in some point of the metabolism, from moderate conditions to extremely serious ones. This is our more traditional strategic work area, where we aim to implement new biomarkers to help identify diseases earlier and predict what the treatment should be.

What can you tell us about the second strategic area, technology?

We are presently partnering with the PKU Foundation, the Autonomous University of Barcelona and the Polytechnic University of Catalonia on developing a sensor for at-home monitoring of molecules in the area of rare diseases. The goal is to monitor a molecule that is altered across different metabolic diseases and which is in turn highly toxic for the brain. This is the epitome of what happens with rare diseases with respect to common ones, since children must be monitored monthly or every two months at best. By contrast, these days nobody thinks a diabetes patient, for example, has to be monitored every 30 or 60 days.

What is the end goal with this project?

In this case, we want to transfer the technology to the home environment and for treatment to take place not only in the Hospital. Children now take their medicine at home and can even sometimes mail in samples. In any case, they are monitored far less frequently.

Is this project already up and running?

We are now facing the trickiest part. The technology has been proven and now we have to transfer this information to industry and capture the attention of someone interested in making the devices.

What can you tell us about the Sant Joan de Déu Research Institute the Hospital is part of?

We developed the Sant Joan de Déu Research Institute (IRSJD) within the framework of the daily activity of SJD Barcelona Children's Hospital and Health Park and it has been part of the CERCA Research Centres of Catalonia group since 2020. The corporate philosophy is to harness support from partners to provide us with basic research and knowledge insights that we may not have developed as fully. For example, we enjoy the support of two University of Barcelona facilities, the Institute of Neurosciences (UBNeuro) and the Institute of Biomedicine (IBUB), as well as one attached to the UPC University of Barcelona, the CREB Research Centre for Biomedical Engineering. These institutions provide their knowledge in neuroscience and molecular and cellular technology, big data, digitalisation, engineering and so on.

What are the challenges facing the SJD Barcelona Children's Hospital Biochemistry Lab?

The challenge is to move towards data analysis that is different to what has been done to date. When we work with a metabolic profile today, we analyse it with a piece of equipment that can examine 500 different molecules. We then use it to seek alterations in different metabolic series, producing a new hypothesis that confirms or rejects the initial information. This is the work protocol we have followed for years and which has yielded very satisfactory results. But now there is the possibility of performing a reverse interpretation since hypotheses can be produced from mathematical studies or from data collected digitally or en-masse (big data). We could therefore say that, in this case, we have a series of molecules we do not want to bias, but rather hope that mathematical analysis can classify patients in a certain way and provide new metabolic clues that may have gone unnoticed with conventional work protocols.

Finally, what do you enjoy doing outside work?

I like walking very much. The pleasure I would find hardest to give up would probably be going for a walk with my wife and some of my four kids. And if we can have a meal together after our stroll, the day can't get any better. ■

"It is hard in Spain to find laboratories that focus on diagnosing specific diseases in the pediatric area".

Gate2Brain wants to deliver drugs into the brain to combat intact blood–brain barrier tumours, such as DIPG

DIPG (diffuse intrinsic pontine glioma) is the most severe of all brain cancers, affecting approximately 2 in every 1 million children. There is currently no cure or effective treatment for this disease, and the mean survival time from diagnosis is only 8–11 months. Gate2Brain is a biotech spin-off made up by SJD Barcelona Children's Hospital, the University of Barcelona (UB) and the Institute for Research in Biomedicine (IRB), which focuses on the development of therapies that efficiently cross biological barriers, such as the blood–brain barrier. Using a patented technology platform based on peptides that improve the transport of drugs into the brain, Gate2Brain aims to combat intact blood–brain barrier tumours, such as DIPG.

DIPG is the most common brainstem tumour. It usually occurs in children between the ages of 5 and 10 years and the symptoms tend to be typical: abnormal facial movements, difficulty swallowing and walking, and lack of strength in the arms or legs. Unfortunately, there is no curative treatment for the disease. While some drugs have shown strong antitumour activity against DIPG in vitro, all of them have failed in clinical trials as they are unable to cross the blood–brain barrier (BBB), which protects the brain but also makes it difficult to treat. The BBB is a protective cell barrier that only allows certain molecules to enter the central nervous system and prevents pathogens and other substances from entering.

Gate2Brain

In July 2020, the Sant Joan de Déu (SJD) Research Institute, the Barcelona Institute for Research in Biomedicine (Barcelona IRB) and the University of Barcelona (UB) created the spin-off company Gate2Brain with the aim of improving the transport of drugs to the brain via a technology based on various families of shuttle peptides. This type of molecule is formed by the union of several amino acids whose aim is to pass through the blood–brain barrier that protects the brain naturally. Once through this wall, the medication can act in the exact site of the disease.

“Although DIPG is one of the most aggressive of all tumours and does not currently have a cure, after many years of research, we know that the blood–brain barrier is intact, which makes it difficult for drugs to reach the site. If we are able to treat this type of tumour with this technology, we are convinced that we will be able to apply it to other diseases in which the blood–brain barrier is intact”, explains Dr Meritxell Teixidó, CEO of the company Gate2Brain.

Innovative technology

Gate2Brain seeks the best partners to conduct each of the activities involved in the process that explores the effectiveness of these shuttle peptides. Research is currently in the preclinical phase, a stage that takes place over several years before clinical trials with human subjects begin, and this is being conducted at SJD Barcelona Children’s Hospital. It consists of evaluating whether these shuttle peptides actually transport the drug to the brain and determining how they act once they cross the blood–brain barrier in animal models of the disease.

The first candidate for transportation to the brain is the drug G2B-002, which is the result of applying the Gate2Brain technology to a potential medication that requires improved transportation, as it alone is unable to overcome the blood–brain barrier. The pharmaceutical industry has invested millions of euros in the development of drugs for central nervous system diseases and the vast majority have never reached patients as they are unable to cross the blood–brain barrier and are therefore unsuccessful.

As Ángel Montero, Director of the Pediatric Cancer Treatment research group at the Sant Joan de Déu Research Institute, explains, “Our research has led us to increase a drug’s concentration in the brain by a factor of 100, and this is key to being able to begin treating a disease sealed by the blood–brain barrier, which is designed to block any foreign substances, as is the case with 98% of medications. Currently, one of the benefits of the Gate2Brain technology is the robustness of its shuttles, which remain in the bloodstream for 12 hours, while the normal time, in the case of peptides, is 15 to 30 minutes. These shuttles have already managed to cross the blood–brain barrier in animal models. Furthermore, the shuttle peptides can adapt to a wide variety of molecules (nanoparticles, proteins, etc.), which shows this platform’s enormous potential to treat various brain diseases”.

Project funding

Thanks to the financial boost given to the project by the Botín Foundation (via the Mind the Gap programme), Banco Sabadell (via BStartup Health), the NEOTEC Programme of the Centre for Industrial Technology Development (CDTI) and the “La Caixa” Foundation (via CaixaResearch Consolidate), extensive work is under way in the laboratory to further develop the research and to obtain funding from private investors both nationally and internationally. ■

Entrepreneurship also takes place in the hospital setting

The use of this technology is not limited to the pediatric population; the discovery may also be useful in adult patients in future

Clinical trial to assess a ground-breaking treatment for polycystic ovary syndrome

SJD Barcelona Children's Hospital is leading an international clinical trial that proposes a treatment for polycystic ovary syndrome, a condition affecting between 5% and 10% of women of reproductive age. The disease can cause an increase in body hair, acne, irregular periods and even fertility problems. The trial is funded by the European Commission and brings together a consortium of 17 key research groups and organisations in Europe that are dedicated to studying polycystic ovary syndrome.

Polycystic ovary syndrome is the most common endocrine disorder in women of childbearing age, but it is also one of the most poorly understood conditions in the population. The condition can also lead to the development of other diseases, such as type 2 diabetes, premenopausal cancer, anxiety or depression, which have a direct impact on quality of life.

SPIOMET4HEALTH is the first registered phase II clinical trial focussing on the baseline (pathophysiological) treatment of this syndrome and not on relieving the symptoms. The study will be conducted in Spain (Barcelona and Girona), Italy, Denmark, Turkey, Austria and Norway.

Polycystic ovary syndrome

Polycystic ovary syndrome is a metabolic endocrine disorder affecting between 5% and 10% of women of reproductive age. Of these patients, 98% receive treatment with contraceptive medication to control their main symptoms: irregular periods, persistent acne, excess hair and difficulty losing weight. "Offering patients contraceptives is all that has been done until now, as it has always been thought that it was an ovarian problem. When you administer a contraceptive, this acts as an ovary and the problem disappears until the treatment is stopped. Contraceptives are even prescribed to girls aged 12 or 13", explains Dr Lourdes Ibáñez, Pediatric Endocrinologist at SJD Barcelona Children's Hospital and Coordinator of the trial.

Dr Ibáñez has been researching polycystic ovary syndrome for decades and has reached the conclusion that ovarian malfunction is not the problem, but rather the consequence. Over the years, Dr Ibáñez has carried out countless abdominal MRIs in patients with polycystic ovary syndrome which have allowed her to observe that the proportion of fat in the liver is higher than would be expected for the patient's age.

"When a woman has significant weight gain from birth until the time she is diagnosed with the disease, she can accumulate excess fat from food intake in the subcutaneous adipose tissue, but if this is not the process taking place, the fat can sediment in the liver, viscera or muscles. This is what causes this abnormality in the ovary", explains Dr Ibáñez. The treatment therefore changes, because if we focus on reducing the fat in the liver, the ovary will function normally once again.

From left to right:
Cristina Salvador, Susana di Giovanni, Silvia Marín, Cristina Garcia-Beltran, Lourdes Ibáñez, Rita Malpique, Maria Elisabet Garcia, Marta Díaz and Marta Ramon

Treatment

The clinical trial aims to assess a treatment based on the administration of one daily tablet to young women and adolescents with polycystic ovary syndrome. This is a medication formulated from three low-dose drugs that have been on the market for decades: spironolactone, pioglitazone and metformin. This medication, combined with a healthy lifestyle, may normalise the hormones and ovulation and, in this way, reverse the abnormalities associated with polycystic ovary syndrome. The drug has little chance of side effects occurring and the only contraindication is that the patient is unable to become pregnant during treatment.

Almost 400 patients will receive the treatment over the course of a year. They will undergo follow-up for another six months to record the changes that occur during and after intake of the drug. A total of 70 patients in Barcelona and 46 in Girona are expected to be recruited. The results will serve as a basis for a phase III clinical trial that will make it possible to use this new approach throughout Europe. The subsequent implementation of the treatment will allow for a saving of between 500 million and 1 billion euros annually for the healthcare system.

Participation criteria for the clinical trial

Participation in this clinical trial is open to women aged between 12 and 24 who have been diagnosed with polycystic ovary syndrome who have irregular periods, excess body hair and/or persistent, excessive acne, and increased concentrations of testosterone in the blood. It is a highly relevant project as, if the medication is confirmed to be effective, it will be possible for the first time to permanently reverse the complications associated with polycystic ovary syndrome, such as infertility, diabetes and low self-esteem.

SPIOMET4HEALTH is being conducted by a research team from the Sant Joan de Déu Research Institute led by Dr Lourdes Ibáñez, who received the Catalonian National Research Award in 2014 and has recently been honoured by two leading international institutions: the American Endocrine Society and the American Human Growth Foundation. ■

98% of the women affected by this disorder receive oral contraceptive treatment to control some of the symptoms

Specialist nurses take charge of 360° patient management

SJD Barcelona Children's Hospital has a long-standing tradition in nursing specialty training. Specifically, the Hospital provides specialised healthcare training in obstetric-gynaecological (midwifery) and pediatric nursing. The hospital's training period is demanding, but at the same time highly thorough, as it provides nurses with a wide range of competences that they can undertake with confidence. The hospital places a specific focus on research training, which gives students a unique perspective compared to other training centres.

More emphasis should be placed on social recognition towards specialist nurses

SJD Barcelona Children's Hospital proposes a comprehensive training programme based on experience and provision of care to children, women and their families. In terms of nursing, the Hospital offers two healthcare specialisations: midwifery and pediatrics. Both specialties are based in the setting of a tertiary-level mother and child specialist hospital that has the highest level of specialisation and complexity and, as a result, has the ideal conditions to carry out all aspects of the training related to pediatrics and gynaecology/obstetrics. These conditions are linked to facilities that strive for excellence at an innovative hospital that is continuously evolving, which allows access to a large number of high-complexity cases.

Pediatric Specialisations

SJD Barcelona Children's Hospital is one of the centres with the most extensive accumulated experience in the training plan for resident internal nurses. This year, it is offering 16 places to professionals interested in highly specialised training in pediatrics, in addition to the 4 separate places for midwifery nursing.

The learning is based on a self-training approach, meaning that rotations must be combined with mandatory lectures for first- and second-year nurses. Furthermore, resident staff should draw on the sessions prepared by the residents themselves, vocational service training and research activity.

"As a resident, I do a day's care at different hospital departments and in primary care. My role is essentially that of a nurse who provides care to children and adolescents. I also carry out non-care tasks in the form of research and teaching. I also attend training sessions included in the training plan that combine theory and practice with case simulation. This is a very enriching learning experience as we are dealing with real-life cases, but in a safe setting", explains Carolina Luján, Resident Nurse specialised in pediatrics.

Other institutions have been added to the training rotations this year, including Casa de Sofía and the Oncology Day Hospital, at which nurses can also undertake external rotations. Both the internal and external training provide nurses with expert knowledge in caring for pediatric patients and their families.

One factor that sets SJD Barcelona Children's Hospital apart is that it is the only Hospital in Catalonia to provide exclusive care to pediatric patients at every level, from outpatient visits to specialisation in the most complex conditions, for which it is a leading referral centre. According to Marta Fajardo, Head of Training and Education Nurses at SJD Barcelona Children's Hospital, the hospital is very demanding in terms of training resident nurses as it expects them to be prepared to put into practice their competences independently at the end of their training period. The effort required over the course of the two years is worth it in the end, as they acquire in-depth, thorough knowledge.

Midwifery

With more than 3,500 childbirths in 2020, the Hospital has a midwife-led care line for low-risk expectant mothers, as well as specialised high-risk units led by gynaecologists and obstetricians who are leading specialists in the area of Women's Health. Qualification for specialisation in obstetric-gynaecological nursing (midwifery) through the residency system was approved in 1992. The Hospital has been involved from the start in this training, provided by the University of Barcelona via accredited centres, this Hospital being one of them. There was a change to the model in 2011 and multi-professional units were set up at the same centres, which took the lead role in providing specialised training. As such, the specialisation in obstetric-gynaecological nursing provided by the Hospital is based at the various units involved in women's health: the delivery ward, the outpatients' department, the Sexual and Reproductive Health Care Unit and the neonatal and specialty units. This rotation provides the nurses with comprehensive knowledge of the specialisation, which consolidates their in-depth training.

The Hospital also places great importance on group work sessions, as the aim is to encourage teamwork, side-by-side, among professionals who do not belong to the same area of expertise. The centre accredited these group training sessions three years ago, with the aim of providing higher-quality teaching.

Raquel Campo, a second-year resident nurse specialising in gynaecology and obstetrics, chose SJD Barcelona Children's Hospital as she was looking for high-quality training. She also appreciated the fact that the Hospital is highly respectful of natural births, in which the midwives play a major role throughout the whole process.

Campo also explains that the tutors provide very close and, at the same time, meticulous supervision, as the aim is to provide maximum support during competence training, resolving any doubts they may have in their day-to-day work and when preparing their research project. To this end, the follow-up that takes place during the nursing residency is extremely thorough.

From left to right:
Raquel Campo, Marta Fajardo and Carolina Luján

Final research project

The nurses who specialised during the pandemic in 2020 took a major step forward in terms of research-related competences. A precedent was set at that time for future graduates. This change involved a significant qualitative leap for specialisations, as it offers residents an added value that enhances their research activity knowledge. ■

The Hospital provides residents with additional training in both case simulation and in the pediatric classroom

Music therapy at home

SJD Barcelona Children's Hospital has implemented a music therapy at home service for children with serious illnesses that are life-threatening or life-limiting, or complex chronic illnesses requiring palliative care.

Every day, a music therapist goes to the children's homes with a guitar in hand and a suitcase full of instruments

It has been 17 years since SJD Barcelona Children's Hospital implemented a music therapy programme for inpatients or those attending day visits. It has now decided to extend the reach of the initiative to beyond hospital walls and take the music therapy to the homes of patients with serious or complex chronic illnesses.

The driving force behind the initiative was actually the mother of a young girl, Anita, who spent long periods of time receiving cancer treatment at the Hospital. Her mother remembers that one of the things they missed the most when Anita moved to the palliative care programme and no longer attended the Hospital was, indeed, the music therapy sessions that cheered up her days when she was an inpatient. Carolina Amado, who now chairs the charity created in memory of her daughter to advance the research and improve the care of children with cancer (Asociación Benéfica Anita), has therefore proposed that the music therapy should also be taken to patients at their homes. This non-profit charity is funding the activity.

This is the first initiative of its kind in Catalonia. Every day, a music therapist from Associació Ressò, the association that collaborates with the Hospital to provide music therapy to inpatients, visits the homes of children with serious or complex chronic illnesses, with a guitar in hand and a suitcase full of instruments (maracas, drums, etc.), to carry out a music therapy session with them. During the sessions, they sing songs or play a variety of musical instruments.

Research study

This initiative, given the name "the travelling suitcase", aims to support the child's well-being and encourage interaction with their parents. "Music makes the brain produce a series of hormones, such as endorphins, that cause happiness, tranquillity and a sense of well-being. It is also a chance for these patients to break away from their usual routine. On the one hand, it encourages care from a different perspective and also allows the children to express themselves and communicate through music, without even realising. It encourages interaction with caregivers and strengthens the family bond, and it improves the patient's emotional well-being, and this is reflected in a way in their physical health", explains Music Therapist Núria Bonet, Coordinator of music therapy at home.

Now, those in charge of "the travelling suitcase", as the initiative is known, want to take it further. To this end, a research study is under way to establish the impact of the music therapy in sick children and their families, in terms of whether it can help make their lives feel more normal, help them experience meaningful life-giving moments, strengthen the family bond, etc.

Before and after the sessions, the music therapists collect various pieces of information to assess the impact of the activity

This initiative aims to support the child's well-being and encourage interaction with their parents

on the child and family's well-being. The research study, which will last for 24 months, will involve a total of 75 patients. During the first year of the initiative, the music therapy has reached 32 children: 17 boys and 15 girls.

Feedback from the families

While awaiting the results of the study, feedback from the families has been very positive. "Today, thanks to the music, we were able to get her to eat after two days without anything", one mother wrote to the music therapists. For Imran's family, the music has allowed them to disconnect and deal with stress. They say "you have a good time, you disconnect, you just do it without thinking, and you have fun. It's also really good for Imran. He's more relaxed."

According to the parents of Siena, a young girl who received around a dozen music therapy sessions at home and who passed away as a result of a neurodegenerative disease last year, it allowed them "something to look forward to and to prepare after each session for the next one", at a time when Siena's prognosis was bleak.

The department's psychologist, Daniel Toro-Pérez, greatly appreciates the initiative and explains that, while awaiting these results, there is already evidence that this intervention provides another insight into getting to know the child and their relatives, strengthening the bond with healthcare professionals, and encouraging the creation of meaningful memories of the child with their family at the end-of-life situation.

Every year, SJD Barcelona Children's Hospital treats 350 patients who require palliative and high-complexity care. Two-thirds are children with serious illnesses who may die during childhood, and the rest are children with complex chronic illnesses. ■

Certification of the advanced practice nurse role recognises the effort, merit and track record of these professionals

In recent years, the increase in complexity of the patients cared for at SJD Barcelona Children's Hospital has made it increasingly necessary to introduce a nursing profile with advanced-level competences. In order to standardise their duties, a process has been carried out to determine the competences that must be met for the advanced practice nurse to become certified.

An advanced practice nurse (APN) is one who has acquired expert knowledge and who has proven experience in the duties assigned, has strong skills for complex decision making and also has the clinical competences for a comprehensive practice. These nurses provide important responses to the health needs of the population and make the service more cost-effective.

Standardisation of duties

Internationally, APNs have a structured role, but there is no standardised framework in Spain that sets out the criteria a nurse must meet to undertake the advanced-practice role, with each hospital setting out its own protocol. Efforts have been made in Catalonia to move towards formally recognising this role, but there is still no single document to standardise the duties to be undertaken by advanced practice nurses.

The advanced practice nursing model at SJD Barcelona Children's Hospital

In an effort to develop its own model, the Hospital took the

Hamric model (2009) as a reference; this is an internationally accepted protocol on the role of advanced practice nursing, which includes comprehensive understanding of the APN and the importance of the role, focussing on a few primary concepts and criteria: postgraduate education, certification in the specialty (expertise in the specific area) and patient- and/or family-centred clinical practice. The Hamric model also determines that these primary criteria should be further defined based on other additional criteria, such as leadership, teaching and research. It is also essential that the professional takes into account the patient's environment, as patients increasingly need ad-hoc care according to their health and social circumstances.

The Hospital's protocol sets out that, after checking that the nurse meets the primary criteria and confirming that they are working with the required additional competences, they must fill in a self-assessment questionnaire, known as "IDREPA", which will later be agreed with their line manager. "IDREPA" is a system that allows staff to carry out a self-assessment to identify whether their profile has the necessary knowledge and skills to be considered as an advanced practice nurse.

The Hospital has two advanced practice nurse roles that provide direct care in specific areas: the clinical expert nurse, who deals with patient care in acute settings, and the case management nurse, who carries out the overall, continuous management of patients referred for chronic conditions.

Inma Rodríguez, Nursing Division Assistant, explains that the plan for 2022 is for the Hospital to certify 10 advanced practice nurses. The number of nurses undertaking this role will increase gradually, but will not be without limit. Inma Rodríguez adds that, in the long term, SJD Barcelona Children's Hospital will need around 50 advanced practice nurses.

Application process

To undertake the role of advanced practice nurse, the Hospital asks that the primary and additional criteria of the Hamric model be fulfilled, that the nurse is in a position that truly needs this role, and that the "IDREPA" self-assessment questionnaire be handed in and administered by the nurse's line manager, who will confirm the information attached. This documentation will be used to draw up a report to be sent to the Nursing Division, together with additional documentation, such as the staff member's CV. The Hospital's evaluation committee, consisting of all the Hospital's management teams, will then evaluate the information provided and make a decision on whether to certify the nurse in this new role.

Recognition of the advanced practice role

Advanced practice nurses have a separate accreditation from the rest of the nurses, as well as financial compensation that recognises their effort, track record and merit. This certification is evaluated over five consecutive years in the form of an updated report and proven results. This follow-up therefore allows the APN's knowledge to be constantly adapted to the setting of patients and their families. Carmen Yoldi was the first advanced practice-certified nurse at the Hospital. She is part of the endocrinology multidisciplinary team, as a diabetes educator nurse in the Outpatient Care Area, and has a career spanning over 20 years in nursing care for diabetic pediatric patients. She has authored various publications in the area of nursing research and is a leading professional in knowledge sharing. Yoldi highlights that she is very proud to be the first APN-accredited nurse at the hospital, not so much for being first but rather for opening up a new pathway in recognition of the care and support provided to patients and their families by nurses. Yoldi also says that she is sure that many more nursing colleagues will soon achieve this accreditation, and thanks the Hospital's Nursing Division for having taken the step to recognise the APN figure, although she believes that efforts must be continued to ensure that the public administration establishes a unified criteria to establish the duties of APNs, not only in Catalonia but all throughout Spain. ■

From left to right:
Emma Gómez, Irune Goicoechea, Inma Rodríguez and Carmen Yoldi

Certification of APNs aims to recognise the value of advanced practice

The Hospital is encouraging nurse training with advanced practice certification

The i4KIDS Pediatric Innovation Hub turns innovative projects into reality in pediatrics and maternal health

i4KIDS is a pediatric innovation network coordinated by SJD Barcelona Children's Hospital, which strives to identify and support innovation projects in the area of pediatrics and maternal health that stand out for their ability to bring about change in society and in pediatric care. It has 28 member organisations, bringing together more than 75 research groups, 32 commercial companies, patient associations, private investors and public administrations. The project is co-funded by the European Union as part of the European Regional Development Fund (ERDF).

The i4KIDS Pediatric Innovation Hub is an initiative led by the Hospital, in collaboration with 28 member organisations, aimed at enhancing knowledge and innovation in the area of pediatrics. The hub also brings together 75 research groups, 32 companies from the industry, patient associations, public administrations and other institutions from the innovation ecosystem in Catalonia. The i4KIDS Pediatric Innovation Hub's mission is to promote and enhance scientific research, encouraging all its members and scientific groups to work towards solutions designed, developed and tested with children. Its values are based on respect, responsibility and commitment to creating a better society, providing real, high-quality solutions in pediatric and maternal health. "The i4KIDS hub's challenge is to create value and social progress to make pediatric care more effective, safer and more efficient for children and their families", explains Xavier Puñet Ortiz, Promoter of the i4KIDS network.

i4KIDS has a multidisciplinary team that provides a wide range of services that allow it to be present in all steps of the innovation process:

- **Expert advice.** The hub puts innovators in touch with the true experts in each specific need: clinics and patients.
- **Viability analysis.** Support is provided by assessing the market opportunity, clinical need and business model of the innovative idea.

- **Funding.** Each project is supported in designing the funding strategy during the initial stages of its development, via contributions from the hub itself and its ecosystem.
- **Development.** The hub has various services, tools and technologies available to help add to the value of each project.
- **Clinical research.** The i4KIDS members are leaders in developing clinical studies in the pediatric population.

Pediatric Innovation Day

Pediatric Innovation Day is a scientific congress organised by the i4KIDS Pediatric Innovation Hub and coordinated by SJD Barcelona Children's Hospital. This annual event brings together experts from the world of innovation, science, entrepreneurship and health in the maternal and pediatric settings, and is aimed at anyone with an innovative project or anyone who wants to support innovation in the area of pediatrics and maternal health.

Pediatric Innovation Day includes a call for innovative projects to be developed in the area of pediatrics and maternal health and which are eligible for a prize awarded by a jury in order to reward the best proposals.

i4KIDS-recognised projects

The Smart Lollipop

The Smart Lollipop is a non-invasive, lollipop-shaped, medical device that aims to detect biomarkers of different conditions in children's saliva. Its aim is to monitor and control children's health with biosensor technology and, therefore, prevent possible risks. The lollipop, which has an electronic reader, shows the diagnostic results in a matter of minutes via an online platform. The staff who developed the tool have concentrated their efforts on using the system to diagnose and monitor coeliac disease, but they plan to extend its use to other diseases in the future. The Smart Lollipop is a medical technology project that received first prize at the 2021 Pediatric Innovation Day.

Gate2Brain

DIPG (diffuse intrinsic pontine glioma) is the most severe of all brain cancers and affects approximately 2 in every 1 million children. There is currently no cure or effective treatment for this disease. Gate2Brain is a biotech spin-off that focuses on the development of therapies that efficiently cross biological barriers, such as the blood–brain barrier. Using a patented technology platform based on peptides that improve the transport of drugs into the brain, Gate2Brain aims to combat intact blood–brain barrier tumours, such as DIPG.

Gate2Brain is a therapeutic project that was a finalist at the 2021 Pediatric Innovation Day.

Blapp

Blapp is a self-adaptive speech therapy rehabilitation platform, with the possibility of remote control and game-form, which allows the therapy to be carried out in the home setting. All of the content is validated by a specialist team and provides support to patients anywhere, reducing the workload of therapists and families.

From left to right: Jaume Pérez, Roser Arnalte, Sofía Ferreira, Cindy Lembart and Àngels Molina (standing), Arnau Valls and Xavier Puñet (crouching)

Blapp is a digital project created in response to a care need and received second prize at the 2021 *Pediatric Innovation Day.*

Neosonics

The Neosonics device, developed by Newborn Solutions, is a sophisticated precision-engineering system that uses high-frequency ultrasound to measure the concentration of white blood cells in the cerebrospinal fluid below the infant's fontanelle, the region of the head in which the bones are not yet closed. Neosonics is the first device allowing neonatal meningitis to be detected via a non-invasive procedure. The only detection system currently available is lumbar puncture. This potentially fatal infection is very difficult to diagnose, particularly in babies, as the symptoms of the disease are very non-specific.

Neosonics is a medical technology project and received third prize at the 2021 Pediatric Innovation Day. ■

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Interferon: a key protein for COVID-19

The Kids Corona platform comprises several lines of research to give specific responses to the different questions raised by the disease and to study how COVID-19 behaves in the pediatric and pregnant populations.

Children may be key to resolving the questions that continue to be raised by COVID-19

Type 1 interferons determine the body's initial response against COVID-19

Several investigators at SJD Barcelona Children's Hospital currently have different lines of research open, including the one that has determined that interferon, a protein produced by the immune system's cells, is key to understanding the body's response to the disease.

The Kids Corona platform is a unique initiative created to determine whether children have a natural protection against COVID-19 and how the disease affects pregnant women. It is an open-access platform so that investigators from around the world, healthcare professionals and the public can join forces to find answers.

According to Juanjo Garcia, Head of Pediatrics, specialist in pediatric infectious diseases and Coordinator of the Kids Corona platform, since the start of the pandemic, the research team has been asking three questions: "whether children become infected with COVID-19, whether they transmit the disease and, finally, why they do not develop the infection in the same way as adults".

At that time, it was already clear that most children would have a mild form of the disease, but there was a small group of children who developed multisystem inflammatory syndrome in children (MIS-C), affecting various organs in the body at the same time. What is most surprising about this unusual syndrome is the fact that the symptoms manifest 4-6 weeks after having had COVID-19.

Within the framework of the Kids Corona platform, SJD Barcelona Children's Hospital continues to have various lines of research open with the aim of solving the questions still raised by COVID-19 today. The challenge is to solve some of the remaining mysteries in the pediatric population and to curb, on the basis of these discoveries, the incidence of the virus in the adult population.

Developed lines of research

Kawasaki syndrome and MIS-C. In 2020, a first line of research was started that analysed the clinical and immunological behaviour of patients with acute multisystemic syndrome in a second phase of COVID-19, which was similar to another previously known inflammatory condition: Kawasaki syndrome. Finally, this research allowed it to be established that, while MIS-C and Kawasaki disease share many similarities, they are not the same condition, as reflected in two publications led by SJD Barcelona Children's Hospital, namely, in the Journal of Clinical Investigation and the Annals of the Rheumatic Diseases.

Laia Alsina, Head of the Allergy and Clinical Immunology Department and Coordinator of the Clinical Immunology Unit at SJD Barcelona Children's Hospital and Hospital Clínic, explains that this collective effort at the global level is enabling us to understand the behaviour of COVID-19, but is also proving useful to better understand other diseases, such as Kawasaki syndrome, which was first recorded in the 1950s but had never previously been simultaneously investigated at the international level.

Interferon. The second line of

research aims to understand the role of interferon in the viral infection, as it is known that interferon is almost always essential in contracting a disease of this type. Interferons are a group of proteins with an antiviral activity involved in the immune response against intracellular pathogens, such as viruses.

When a cell is infected by a virus, it secretes interferons, a type of cytokine that are crucial proteins for controlling the growth and activity of other immune system cells. Interferons activate antiviral defences in cells close to the infected cell to limit the spread of the virus.

In recent months, it has emerged that type 1 interferon plays a significant role during the initial phase of the disease in children, which helps children to develop a mild form of the disease. On the other hand, interferon loses intensity in adults and, as a result, the body has less protection against COVID-19.

The investigators leading the study, Iolanda Jordan, expert in Pediatric Intensive Care and investigator at the Biomedical Research Networking Centre for Epidemiology and Public Health (CIBERESP), and Laia Alsina, Head of the Allergy and Clinical Immunology Department, have compared the response of interferon and other cytokines in over 80 patients, both adults and children, who have been infected by SARS-CoV-2 and have had varying degrees of severity. Their aim is to identify markers that allow to predict, at the time of diagnosis, which patients will develop a severe form of the disease in order to personalise the future treatment, and to differentiate the condition from other diseases with a systemic inflammatory component, such as sepsis.

Cytokines. The third line of research focuses on understanding why, in cases in which there is such a significant MIS-C-type inflammatory response, such as in some children with COVID-19 in a second phase of the disease, there is also a minimal interferon reaction. To this end, it has been demonstrated that low levels of expression of the CIITA gene and high levels of expression of the SOCS1 gene are correlated with the most severe cases of COVID-19.

This leads to an inefficient antiviral response at an initial stage, together with development of a perfect storm of cytokines, which are small proteins that act as messengers between the different immune system cells and which, in turn, are responsible for coordinating an effective immune response to fight the infection. All these elements together subsequently lead to multisystemic organ inflammation. These results, which were published in the iScience journal, indicate that analysis of the expression pattern of some cytokines and the selected genes could be used in the future as biomarkers to identify patients at higher risk of developing severe COVID-19, which could open the door to new therapeutic options to approach this disease.

SJD Barcelona Children's Hospital has also started another line of research, in collaboration with the COVID Human Genetic Effort international consortium, to determine whether there are genetic factors that, in one way or another, predispose a patient to developing COVID-19.

As Iolanda Jordan explains, having increasingly more information about this virus has meant that the drugs given to pediatric patients have been changing. Initially, the medications were aimed at stopping the infection. However, when it was observed that what is harmful to patients is the organ inflammation, priority was given to immunomodulatory therapy. Jordan adds that we are still a long way from having a preventive approach, but that we have advanced greatly in terms of treatment administration. ■

Children have higher type 1 interferon levels than adults, which would explain why COVID-19 has a lower incidence and is milder in the pediatric population

SJD Pediatric Cancer Center Barcelona

A monographic centre for pediatric cancer, unique in Spain, and one of the largest in Europe and worldwide.

Pediatric Cancer Center
Barcelona Children's Hospital