PAIDHOS

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The *Únicas* Network: 30 hospitals in Spain join forces to improve care for pediatric patients with rare diseases

SJD
Sant Joan de Déu
Barcelona · Children's Hospital

Research and innovation are essential aspects for improving our health system and, therefore, hospitals. Furthermore, if hospitals are not only able to bring about know-how but also to share it, our work would be even more greatly appreciated by patients and their families, who ultimately most deserve to reap its benefits.

This is why the Únicas project has now been set up. It is a network of 30 hospitals in Spain that have come together to improve the care given to pediatric patients with rare diseases. The Ministry of Health and the autonomous governments of Spain have made a firm commitment to the network through the Inter-Regional Board of the National Health System. Through this initiative, driven by SJD Barcelona Children's Hospital and the Spanish Federation of Rare Diseases (FEDER), the aim is to prevent what is currently happening to one in four children affected by a rare disease, which takes 10 years or more to obtain a diagnosis and treatment.

In this issue of the journal Paidhos*, we discuss this project, including a report about Covadonga, the mother of Alonso, who had to consult various specialists in different cities for 5 years until she was given a diagnosis at our hospital.*

In addition, the magazine includes examples of how technology helps us to improve the quality of life of patients, as is the case of remote cardiac monitoring and nuclear medicine, whilst not overlooking more humanistic approaches, such as pain management and projects for the prevention of illnesses and the promotion of health, especially mental health in young people, at a time they are finding complex. The Henka programme, which we talk about in this issue, can help them overcome emotional distress based on the idea of resilience as a construct.

Manel del Castillo, Managing Director of
SJD Barcelona Children's Hospital

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Summary

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Únicas
Raras pero no invisibles

30 hospitals in Spain join forces to improve care for pediatric patients with rare diseases

30 Spanish hospitals have joined forces, creating a network to improve care for pediatric patients with rare diseases. The objective of the Únicas network is to offer a global solution for pediatric patients who suffer from rare conditions, taking into account the needs of the care process – from diagnosis to treatment – as well as social and family needs.

The Únicas Network is an initiative led by SJD Barcelona Children's Hospital, and the Spanish Federation of Rare Diseases (FEDER). It involves the Ministry of Health as well as the autonomous governments via the National Health System's Interterritorial Council.

According to Juan Carrión, president of FEDER, "Through this network we would like to prevent families travelling from hospital to hospital in order to successfully identify their child's condition. For this reason it is a pleasure for FEDER to collaborate, it is an excellent example of networking, striving to collectively improve care."

In his opinion, "Knowing the name of the disease, making an early diagnosis a reality, is key in enabling specialists to focus their efforts on searching for treatments which contribute to an improved quality of life for patients and their families."

For his part, Manel del Castillo, Managing Director of SJD Barcelona Children's Hospital reiterates that the Únicas network, "Is a project which seeks to deliver a comprehensive response for pediatric patients with rare diseases. Our aim is to reduce the time waiting for a diagnosis, through collaboration between centres and the sharing of information. It's about moving knowledge, not patients."

He adds, "This also has an impact on gender issues, as usually the person who gives up work to take care of the child's needs is the mother, she is the one who has to leave her career and home to move to another area so she can take care of her child. This is something which can be changed."

According to Manel del Castillo, "We are a network of 30 hospitals, creating a technological platform to share data. This will enable us to improve the multidisciplinary care model, increase patient accessibility thanks to telemedicine, improve diagnosis through precision diagnostic techniques, and provide equal access to advanced therapies."

Effectively, the 30 hospitals will work together to offer a holistic 360° healthcare model which will be developed across 3 platforms.

- **Data platform,** which will enable the federated sharing of data amongst all the stakeholders involved in care, using a specific technological infrastructure. Each partner centre will retain their own information, but will agree to share the information needed to generate knowledge, enabling a move towards personalised prediction and prevention.

- **Support research platform**, the objective of this will be to reduce the number of patients without a diagnosis and to increase the number of specific treatments through the development of precision diagnostic techniques and advanced therapies. These advances will be developed jointly with hospitals in the network and the universities, research centres, pharmaceutical industry and healthcare technology companies involved in the project.

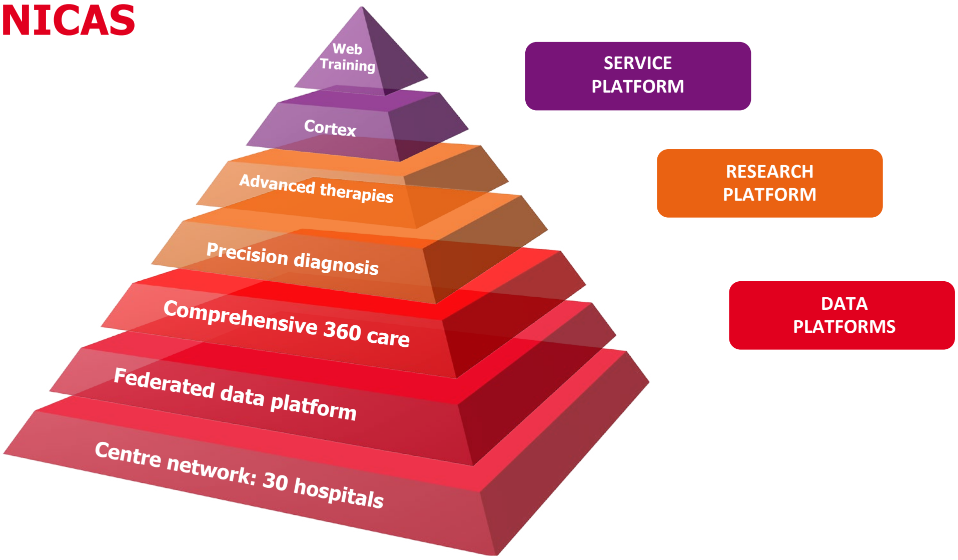
- **Service platform for patients and carers.** A specialised telemedicine centre (CORTEX), a web platform adapted to the needs of patients and their families, and a carers' school (UNICAS ACADEMY) enabling improved patient access to the care they need.

Diagnostic difficulties

The existence of more than 10,000 rare diseases, some of them ultra-rare (only a few cases in the entire world), hinders diagnosis, as they are unknown even to many healthcare professionals.

From left to right: Manel de Castillo, Managing Director of SJD Barcelona Children's Hospital; Meritxell Batet, President of the Congress of Deputies; Juan Carrión, President of FEDER, and Javier Cobas, Deputy Managing Director of La Paz University Hospital.

UNICAS



The aim is to launch a health centre network to improve the care of pediatric patients with rare diseases

Early diagnosis is key to finding treatments which improve patients' quality of life

"It's about moving knowledge, not patients."

This situation lead to many children waiting years to obtain a definitive diagnosis, whilst undergoing dozens of tests and visiting numerous specialists. Currently the average time from presenting initial symptoms of the disease to reaching a diagnosis is four years. But for 25% of these patients, it is 10 years or more.

Representative samples

The collection of representative samples from patients affected by a rare disease promotes understanding of the disease's natural history and drives research into finding new treatments. Currently, 95% of rare diseases do not have a specific treatment.

One of the main handicaps encountered by investigators in driving studies to discover new treatments is obtaining a significant sample of patients. As these are rare diseases, the number affected in an autonomous community is very low, making it necessary to search at a national and international level.

Access to advanced treatments for all

Another of Únicas' objectives is to guarantee that all patients, independently of where they live, have access to the most advanced treatments for their disease and to the necessary healthcare resources. To achieve this, the network anticipates that health professionals who form part of Únicas will maintain contact using telemedicine to form a consensus with the relevant professionals on the action to be taken for a specific condition.

Presentation at House of Commons and Health Minister's visit

On 28th February, coinciding with Rare Disease Day, the Únicas network was presented at the House of Commons. The event was attended by the Congress President, Meritxell Batet, the Minister of Health at the time, Carolina Darias, the Managing Director of SJD Barcelona Children's Hospital, and the FEDER President. The members of The Board of the Congress, the Health and Consumer Affairs Commission and Congress spokespersons were also present. Furthermore, the current acting Health Minister, José Miñones, visited the SJD Barcelona Children's Hospital on July 6, where he anounced approval from the Spanish Government for 42 million euros to be allocated to support the development of the Únicas network. The minister emphasised that this project was a matter of urgency and a priority for his department. He also highlighted, "Únicas will make a qualitative and quantitative leap possible in the care of girls and boys who suffer from rare diseases throughout the country." ■

KEY FACTORS

- **Normalisation:** standardisation and protocolisation of methods of working.
- **Healthcare model:** providing a holistic view of the patient, from beginning to end, the disease being addressed by a multidisciplinary team with the geographical location being irrelevant.
- **Proximity:** provision of support to families and carers throughout the process.
- **Accessibility:** provision of care for patients remotely, from whichever network node.
- **Sustainability:** a stable approach, possibility of continued expansion and improvement.
- **Common process:** achieving a basic common process through consensus, for the entire Únicas network.

The experience of Alonso's family

After presenting the initial symptoms, 25% of children currently affected wait 10 years or more to receive a disease diagnosis.

Alonso is a 10-year-old boy who lives in Asturias (Spain) and who has a rare disease called KCNQ2 epileptic encephalopathy. The symptoms of this condition appeared shortly after birth in the form of seizures but, his parents did not obtain a diagnosis until he reached the age of five. Meanwhile, he suffered other health problems affecting his digestive system and sight as well as having a motor delay.

During those years, Alonso's family consulted specialists in different cities without obtaining a diagnosis. Finally, a team from the Neurology Department at SJD Barcelona Children's Hospital was able to establish a diagnosis and start treatment to tackle his symptoms, as there is still no cure for his condition. His mother, Covadonga, believes that the launch of the Únicas network will be a giant leap forward in care for these patients. "If only a network of this nature had existed to offer me all the information available on my son's disease, it would have saved me many sleepless nights searching for information about Alonso's symptoms, trying to understand how many children there were in the same situation as him, and looking for treatments which could be useful and experts who could treat him."

Covadonga has lost count of the journeys she has made to Madrid and Barcelona in the last 10 years, "If the doctors who treat these children are able to access the leading experts in rare diseases and understand which tests are appropriate in each case, this will save the families affected from making multiple trips, our children will only have to travel when absolutely necessary - to undergo tests or investigations which cannot be done in their home town." In her opinion, "This is highly important. Not only due to the financial costs involved in making these journeys, which is significant, but also due to the upset caused to the children." ■

Remote cardiac monitoring improves clinical results in the pediatric population worldwide

In 2012, SJD Barcelona Children's Hospital pioneered the implementation of a remote cardiac monitoring programme for pediatric patients with a rare disease, laminopathy, who are at high risk of suffering serious arrhythmias. Over time, their experience has continued to grow and today the eRITME programme enables monitoring, throughout the world, of several arrhythmic syndromes related to sudden death.

In recent years, technological developments have made it possible to overcome barriers which until not long ago were considered insurmountable. Undoubtedly, one of the fields in which advances have been most significant is that related to remote monitoring. The miniaturisation of equipment and improvements in wireless connection have enabled the exploration of telemedicine. This has provided several solutions, weakening the traditional concept of a hospital and moving towards a fluid hospital, where communication with patients, through the medium of the latest technology, allows a more accessible healthcare model and facilitates remote care.

In line with this philosophy, in 2012 SJD Barcelona Children's Hospital Arrhythmia Unit, together with the Andres Marcio Foundation – Children against Laminopathy, launched a pioneering programme to monitor patients with laminopathy throughout the world. Laminopathy is a rare, congenital neurodegenerative disease affecting the muscles, including the heart. The good results obtained encouraged us to expand the indications. Today, the eRITME programme remotely monitors 500 patients around the globe, with different arrhythmic syndromes related to sudden death such as long- QT Syndrome, Brugada Syndrome, cardiomyopathies, TANGO2 and other metabolic diseases, as well as laminopathy and other neuromuscular diseases.

"The great challenge we have always had to deal with is the lack of equipment developed for pediatric patients. We have had to be imaginative and adapt equipment which was created for adults. Now, thanks to our use of them, the tools which we started to use off label already have a significant amount of evidence and their use is quite clearly recommended," explains Dr Georgia Sarquella-Brugada, leader of the Arrhythmia, Family Cardiopathy and Sudden Death Unit at SJD Barcelona Children's Hospital.

CORTEX and ENIGMA, Centralisation tools

The ability to reduce the size of equipment even further, together with the tools which have im-

proved connectivity, have meant that data collected has grown exponentially, advancing from almost none to an amount of data so large that it poses new challenges, such as how to better make use of it or how to filter it in a precise and appropriate manner.

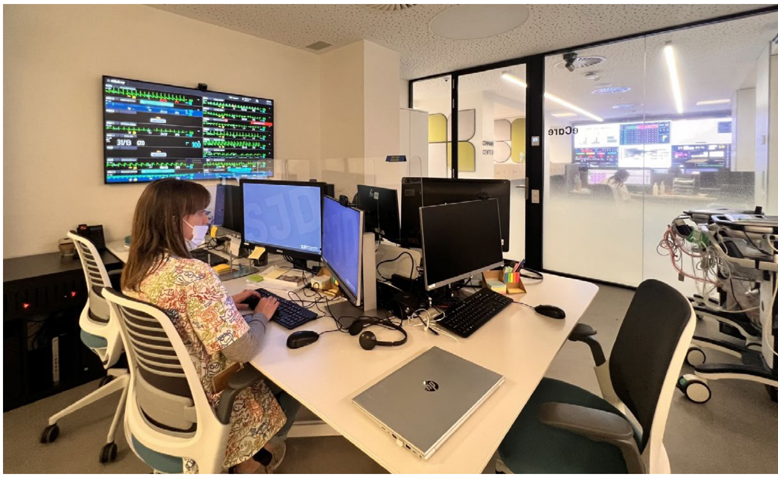
During this growth, SJD Barcelona children's Hospital has developed a structure, the CORTEX, which includes the collection of data. Bearing in mind that patients come from all over the world, the ENIGMA platform is being adapted to centralise all the data collected by different monitoring systems, enabling monitoring 24 hours a day, so that the whole arrhythmia team can identify any deterioration at an early stage.

"Many journeys to the centre can therefore be avoided, in some cases these journeys can be complex, even requiring air travel. We are now able to monitor treatment remotely, identifying whether changes are successful, without the need for travel," adds Dr Georgia Sarquella-Brugada, who also explained the significant positive impact this has on pediatric patients, who no longer need to experience the stress of leaving their home, or missing school, also for their parents who do not have to take time off work. Furthermore, it is in harmony with the idea of improving sustainability in the healthcare system, preventing unnecessary travel.

Evidence of the advantages

Throughout this time, the collection of a significant amount of data has been possible, endorsing the benefits of remote cardiac monitoring in pediatric patients. A resulting reduction of up to 45% in hospital visits has been achieved, along with earlier detection of any problems, thus allowing more rapid decision making, as she explains, "Ultimately this has also resulted in a reduced mortality rate." However, it is hoped that this remote monitoring can be developed further, to this end, the development of artificial intelligence algorithms to help to manage the data collected will be essential. "Once again the problem we encountered was that all existing algorithms were developed in adult patients, and we now have to adapt them for our patients," explains Dr Sarquella-Brugada, who recognises that it will also be necessary to take advantage of the data obtained to publish new scientific articles enabling the knowledge generated to be available for everyone.

"Ultimately, these tools allow strict monitoring, despite the distance, enabling us to take control of the disease. It comes down to putting the patient at the centre of the care process, with individualised treatment. To achieve this, monitoring provides valuable knowledge and enables us to overcome classic problems such as lack of continuity of care. ■



Twenty years of research in childhood oncology

SJD Pediatric Cancer Center Barcelona (PCCB) at SJD Barcelona Children's Hospital has launched its new facilities in the Childhood Cancer Research Unit - CaixaResearch, on the 20th anniversary of the laboratory's creation. The laboratory was created in 2003 and has grown thanks to CSO donations. The new space has been subsidised with 3 million euros from the "la Caixa" Foundation and by patients' families and other Civil Society Organisations, which have provided contributions obtained through organising various initiatives.

The Unit boasts 1,112 square metres for new equipment, incorporating two defined spaces, one for a molecular diagnostics laboratory and the other allocated specifically for research.

"Initially, molecular study of tumours was only performed in very specific cases and more for reasons of research than healthcare. It is now carried out in all cases. Molecular diagnostics in tumours is essential to provide a prognosis regarding their development and to determine which is the most appropriate treat treatment for the child, this is known as precision or personalised medicine. It forms part of standard treatment," highlights Jaume Mora, Scientific Director at SJD Pediatric Cancer Center, Barcelona.

In the research laboratory, a team of 50 researchers are dedicated to studying a wide variety of developmental tumours: neuroblastoma; medulloblastoma; retinoblastoma; Ewing sarcoma; diffuse brainstem glioma or DIPG; high-grade pediatric glioma; rhabdomyosarcoma; osteosarcoma; leukemias; vascular tumours; histiocytosis and low-grade gliomas.

Key developments

Some of the research work carried out throughout the last two decades has enabled improvements in the diagnosis of some cancers and personalised treatment to be developed. In practice, these advances have made it possible for some children to be treated successfully without the need for chemotherapy. For others, who present very aggressive tumours, treatment has been made possible with very personalised therapies, targeted at the tumour's specific molecular abnormalities.

One prime example is neuroblastoma, a tumour which originates in the immature cells of the peripheral nervous system. Initially, the research team which started to work in SJD Barcelona Children's Hospital Childhood Oncology Laboratory focused on research into this tumour, the most common during the first five years of life.

In 2012 these researchers identified several genetic markers which allowed the aggressive nature of neuroblastoma to be predicted immediately after diagnosis, within 24 hours. This information is key, it has currently made it possible for half of patients with neuroblastoma to overcome their disease by undergoing surgery alone, without requiring chemotherapy or radiotherapy.

In parallel, professionals at SJD Barcelona Children's Hospital participated in trials of immunotherapy treatment for high-risk neuroblastomas, markedly improving survival (from 35% to 75%). The monoclonal antibody (naxitamab), created at Memorial Sloan Kettering Cancer Center in New York, and developed by a company founded by the father of an American patient, was given for the first time in the world to a patient at SJD Barcelona Children's Hospital in 2017. Naxitamab has now patients worldwide. Researchers at SJD Barcelona Children's Hospital have also played a significant role in advances against retinoblastoma, or retinal cancer. For the first time globally they have developed, together with VCN Biosciences biotechnology company, an oncolytic virus which has prevented three children from losing their sight completely. The virus is an adenovirus, a virus responsible for cold symptoms, which has been modified in the laboratory making it able to identify, infect and multiply in cancer cells, attacking them selectively and leaving healthy cells unharmed. ■

An invaluable tumour bank for researchers

Researchers at the Childhood Oncology Laboratory have access to the largest pediatric tumour bank in Spain to carry out research. For the last fifteen years, the Pathology Department has systematically collected all the tumour specimens removed from patients throughout their disease. This has been for two reasons, firstly, to be able to offer patients molecular diagnostics and personalised treatment and secondly, to advance research into developmental tumours, making it available for researchers throughout the world. "The patient is always the priority. When they arrive in the Pathology Department the pathologists select the specimens. One part of each specimen is reserved for the hospital pathologists to make a disease diagnosis, the surplus is preserved for use in research," explains Cristina Jou, the person in charge of the Biobank at SJD Barcelona Children's Hospital. Currently SJD Barcelona Children's Hospital's tumour bank contains more than 4,200 tumour specimens. In addition to these frozen specimens, the Biobank also contains paraffin embedded specimens as well as DNA and RNA.

Cryopreservation of specimens has been possible in more than 700 of these tumours, enabling tumour cell cultures. As Cinzia Lavarino, head of the molecular diagnosis laboratory explains, "It is extremely valuable material for researchers. We must remember that childhood cancer is a rare disease, and having sufficient tumour material available is a challenge which we, the researchers, face when driving research forward. ■

New nuclear medicine unit to improve diagnosis and research into pediatric disease

The SJD Barcelona Children's Hospital's new Nuclear Medicine Unit has been up and running since February 2023, offering new diagnostic imaging options and treatments for children with various illnesses—cancer in particular—and opening up new approaches for research into pediatric cancer.

The new unit is managed by Atrys Health, a global company specialising in preventative, diagnostic and curative medical services, through their SIMM Molecular subsidiary. It is based in the SJD Pediatric Cancer Center Barcelona as a large percentage of patients who require this service are found to have a tumour.

During the opening ceremony in February 2023, Manel del Castillo, the managing director of the SJD Barcelona Children's Hospital, said "The Medicine Unit is a huge step forward for diagnosing, treating and researching the rare, complex diseases that many of our patients have, which is hugely valuable to the SJD Pediatric Cancer Center Barcelona". Each year, around 1,400 patients at the SJD Barcelona Children's Hospital require diagnostic imaging at the Nuclear Medicine Unit. They are mainly oncology patients, but there are also patients from nephrology (urine infections, transplants, obstructive endocrinology (thyroid gammagraphy and hyperthyroidism treatment), neurology (assessment for epileptic seizures and energy needs of each brain region), rheumatology (bone density) and traumatology. Santiago de Torres, president of Atrys, announced that the new unit allows 'not only for faster diagnosis, but also an improved prognosis for childhood cancer patients thanks to revolutionary medical equipment. It also makes it much easier to treatment. This collaboration with the SJD Barcelona

Children's Hospital is yet another example of our commitment to medical excellence, to ongoing improvement to healthcare quality and to diagnostic precision".

Research in oncology

The new facilities also help drive progress in the research and treatment of pediatric tumours, also known as childhood cancer, making it much more achieveable. The facilities include two new lead-lined metabolic therapy rooms, where tumours can be treated with radiopharmaceuticals.

Our new therapeutic options make use of radionuclide drug conjugates (radioactive drugs) to target specific tumour features that have been marked using antibodies (immunotherapy), radioimmunotherapy. This makes new treatments more targeted and much more effective.

SJD Pediatric Cancer Center Barcelona and SIMM will launch several lines of research into new markers to help expand the capabilities of radioimmunotherapy in the future to include all kinds of solid pediatric tumours.

The new Nuclear Medicine Unit, which also treats adult patients, has three cutting-edge devices for metabolic tumour diagnosis, making use of advanced imaging techniques such as PET-CT and SPECT-CT, as well as featuring two lead-lined treatment rooms. ■

Every year, around 1,400 patients at the SJD Barcelona Children's Hospital need a diagnostic test at the Nuclear Medicine Unit

Precision medicine to treat pediatric cancer

The SJD Pediatric Cancer Center's Precision Oncology Programme at the SJD Barcelona Children's Hospital has successfully treated a child with a very aggressive brain tumour using two drugs normally used for lung cancer in adults.

Molecular abnormalities can be identified in every tumour, allowing healthcare professionals to then offer more personalised therapies.

This programme, which has helped over 400 children and teenagers since 2019, aims to not only achieve a more precise diagnosis of each patient's specific type of cancer, but also identify molecular mutations in the tumour that may require a more personalised therapeutic approach. Take Makar's case, for example.

He was diagnosed with a severe brain tumour—an infant high-grade glioma— in 2018, when he was only months old. He was operated on and received chemotherapy in his hometown of St Petersburg, but it was unsuccessful.

When oncologists in his country were unable to offer another option, the family got in touch with the International Patients Department at the SJD Barcelona Children's and sent a sample of the tumour so that our Precision Medicine team could carry out.

The molecular study revealed that Makar's tumour had a mutation involving the ALK gene, which is common in adult lung cancer cases. 'When we found this mutation,' recounts Andrés Morales, Chief Medical Officer of the SJD Pediatric Cancer Center Barcelona, 'our precision oncology team started searching for drugs that could target this abnormality. We needed a drug that could target this specific ALK- mutation, and that, more importantly, would properly reach the brain. Many drugs struggle to affect this area of the body as they cannot cross the blood-brain barrier, which helps protect the brain from harmful substances (including many medicines). This is positive from an evolutionary standpoint, but rather negative when to reach the brain and treat certain diseases like this one.'

Two ALK gene mutations

This wass the first time ever that this medication would be administered to a child in this situation. As such, oncologists at the SJD Barcelona Children's Hospital got in touch with the pharmaceutical company to enquire about the dosage that would be best tolerated by the child, and the most effective. Weeks after receiving treatment, an MRI showed that the tumour had gotten significantly smaller, almost completely disappearing.

Three months later, however, the glioma had become resistant to treatment and had begun to grow again. Neurosurgeons at the SJD Barcelona Children's operated on Makar again, removing the entire tumour so it could be sent off for analysis.

The study detected a second mutation in the same ALK gene. Oncologists then decided to administer another drug that was also indicated for adult lung cancer. Once more, they had to contact the corresponding pharmaceutical company, as this other drug had never been used in cases like Makar's. The second treatment once again managed to reduce the tumour, only for it to regrow. The child had another operation and started proton beam radiotherapy immediately after. He finished treatment in December 2022, and more than one year later, the tumour was still gone and there were no signs of the disease. ■

More than 400 children and teenagers have benefitted from the Precision Medicine unit at the SJD Barcelona Children's Hospital since 2019

The CAR-T ARI trial begins for children with lymphoblastic leukemia

Last May, the SJD Barcelona Children's Hospital started a new academic phase clinical trial to evaluate the efficacy of CAR-T ARI-0001 in pediatric patients. It was developed in partnership with Hospital Clínic, and named in memory of the patient who promoted it and made it possible through a sponsorship campaign. This treatment was approved in 2021 by the Spanish Agency for Medicine and Health Products (AEMPS), for hospital use in treating adults over the age of 25 with type-B lymphoblastic leukemia, which is resistant to conventional treatments.

The approval of the academic phase of CAR-T came about thanks to good results obtained in an initial trial of ARI in children and adults with type-B lymphoblastic leukemia, which was carried out by both the SJD Barcelona Children's Hospital and Hospital Clínic. Although results were good in pediatric patients, it was only approved for use in adult patients in 2018 because an industrial pharmaceutical CAR-T (Kymriah) had already been approved for pediatric patients. Now, the CAR-T ARI clinical trial has been opened to pediatric patients in less advanced stages of the disease to find out whether this treatment could be used to substitute others that carry more risk and side-effects, such as a bone marrow transplant.

A 7-year-old girl has been the first patient to receive this immunotherapy treatment within the framework of the clinical trial, which is expected to last two years and have around 30 participants from all over Spain.

According to Susana Rives, head of the Leukemia and Lymphoma Unit at the SJD Pediatric Cancer Center Barcelona (PCCB) in the SJD Barcelona Children's Hospital, 'CAR-T is a therapy that arms the patient's own immune system with the tools it needs to recognise, attack and destroy cancerous cells in a targeted way.' She adds, 'It involves taking a blood sample from the patient through apheresis—a technique that allows blood components to be separated—to obtain T- lymphocytes, a cell found in the patient's immune system.'

These lymphocytes are modified in the lab with genetic engineering techniques to have a receptor on the cell surface that can recognise tumour antigens expressed by type-B leukemias and lymphomas. This allows for targeted destruction of cancerous cells.

The SJD Barcelona Children's Hospital was one of the first hospitals in Europe to start working on CAR-T therapies in children. In 2016, it was the only hospital in Spain that took part in the clinical trial studying the safety and efficacy of a CAR-T developed by the pharmaceutical company Novartis. This was the first pediatric-targeted therapy to be approved by the European Medicines Agency (EMA) and included by the Spanish Ministry of Health in their service offering for treating acute lymphoblastic leukemia in secondary relapse. With the development of the academic phase CAR-T ARI, researchers hope to find a new therapy that can be used in first relapses of the disease. The CAR-T ARI clinical trial for pediatric patients that has been started now is being carried out within the framework of the pediatric research plan developed by Hospital Clínic and the SJD Pediatric Cancer Centre at the SJD Barcelona Children's Hospital, with the aim of CAR-T being approved in the future by the European Medicines Agency, both for adult and pediatric use.

Cleanrooms for developing advanced therapies

The SJD Barcelona Children's Hospital is almost done implementing a platform of four advanced therapeutic treatments can be developed and produced. This is an innovative therapeutic effort involving the use of biological or genetically modified materials in disease treatment. Thanks to this new infrastructure, the Hospital can begin producing CAR-T cell therapies and investigate new treatments, such as gene therapy for primary immunodeficiency in pediatric patients, who, at present, have no efficient treatment option.

These rooms are intended and designed to guarantee an extremely high degree of environmental control, ensuring a sterile environment, and avoiding any risk of contamination during the development of drugs or advanced therapies. The rooms meet the highest quality standards in industrial pharmacology and are approved by the Spanish Agency of Medicines and Medical Devices (AEMPS), to produce these therapies. This is particularly important, especially taking into consideration the situation: a pediatric hospital like SJD Barcelona Children's Hospital, a hospital specialised in pediatric cancer, where countless children with rare diseases are treated. It allows us to make progress with SJD Barcelona Children's Hospital translational research model, which aims to apply research results to clinical practice as soon as possible.

The cleanrooms are part of the Pediatric Infrastructures for Viral Therapy project (PIVIT), coordinated by lead researcher Manel Juan, head of the Immunology Service at Hospital Clínic and of the joint Immunotherapy Platform of SJD Barcelona Children's Hospital and Hospital Clínic Barcelona. This project is co-financed by the Generalitat de Catalunya's Ministry of Research and Universities. They will provide the Hospital, the SJD Pediatric Cancer Center and the IRSJD, the SJD Research Institute, with facilities that will fuel research and innovation with the highest standards of investigative excellence. ■

The SJD Barcelona Children's Hospital was one of the first hospitals in Europe to start working on CAR-T therapies in children

Delayed-interval deliveries

For twin births, when the first baby is born before the 28-week mark, staff consider delaying the birth of the second baby as long as possible to increase the chances of survival.

Staff at the SJD Barcelona Children's Hospital have attended eight different delayed-interval deliveries in just five years, including the birth of child with the longest delayed delivery ever recorded in Spain where both babies survived.

Ian was born on the 17th of January last year, and his twin sister, Laia, on the 26th – nine days later. They came into the world through what is known as a delayed-interval delivery. This is a very uncommon procedure that medical professionals only turn to in cases of very premature twin births.

When the first baby is born before the 28-week mark, the medical team treating the mother can try to delay the birth of the second baby, thereby increasing both time in the womb and chance of survival.

There are several requirements that must be met: the first birth must be vaginal; the twins must be dichorionic (meaning there are two different placentas); and after the first baby is born, contractions must stop and there must be no risk of infection for the mother or babies.

Eight delayed-interval deliveries in five years

Staff at BCNatal, the Obstetrics and Gynecology Department at the SJD Barcelona Children's Hospital, have handled eight delayed-interval deliveries in the last five years. According to the scientific literature consulted, one of these deliveries was the longest delayed-interval delivery ever recorded in Spain in which both babies survived: twins who were born 48 days apart. "We have had delayed-interval deliveries with a longer latency period, but in these cases the first baby does not survive due to being born so prematurely. The child is either stillborn or passes away in the first few days of life' explains Silvia Ferrero, obstetrician at the SJD Barcelona Children's Hospital.

Only facilities that have a neonatal intensive care unit and a skilled team with experience in high-risk pregnancies can handle a delayed-interval delivery. Firstly, there needs to be a neonatal PICU that can provide all of the necessary care that a very premature baby requires. Then, the obstetrics team needs to be extremely well-versed in high-risk pregnancies so that they can monitor the mother properly and avoid any uterine infections or other complications that could endanger her life or that of the baby still in the womb. This team must monitor the mother through regular check-ups, with blood tests, cultures, ultrasounds and amniocentesis, to detect any complications as early as possible and decide when is the most appropriate time for the second delivery. ■

Ian and Laia's mother, Laura 'We thought that once Ian was born, Laia would be here straight after, but that wasn't the case. She came nine days later! I wanted us all to be together as soon as possible, but I realised that every extra minute she spent in my womb was so important for her. Laia was born stronger and didn't need respiratory support'.

Huddles, a tool for improving communication

Since 2017, SJD Barcelona Children's Hospital has adopted the LEAN philosophy to improve healthcare quality management. Originating in the car industry in Japan, this methodology has been applied to different fields, and was first implemented in the healthcare sector in 2001 in the United States. One of its key tools is the huddle, which has a tried-and-tested application at SJD Barcelona Children's Hospital.

One of a hospital's main concerns is to ensure that its quality of care is as high as possible. So it is necessary to have highly-trained expert professionals, and equipment and facilities suited to the activity carried out there. However, these two inputs do not always guarantee that the quality of care will be as good as it should be. There is a whole set of processes that make the hospital's gears truly work in the best possible way.

Lean Manufacturing is a philosophy that emerged in Japan in the 1950s at the Toyota car company. However, it began to take shape much earlier, at the end of the 19th century, when Sakichi Toyoda added a device to weaving machines that could detect incidents and quality problems in garment manufacture. Toyoda wanted to create a production setting in which machines, facilities and people worked in complete harmony and synchronisation, with the aim of producing without generating castoffs, eliminating any waste between the different operations in the process.

In recent times, this philosophy has been applied to different areas, adapting to their characteristics. In 2002, the Virginia Mason Medical Center in Seattle, USA, was the first to adapt it to healthcare, creating Lean Healthcare. Later, in 2017, SJD Barcelona Children's Hospital adapted it to reflect the character and values that differentiate the centre. "When we started to incorporate this philosophy into our hospital, it was clear that we had to take our own idiosyncrasies into account. Concern for the person is fundamental to us; issues such as spirituality should not be neglected," explained Susana Ortiz, Head of Processes at the Quality and Patient Experience Department at SJD Barcelona Children's Hospital, who highlighted that the hospital is a pioneer in implementing this philosophy in health centres in Spain.

Improving communication

Lean philosophy makes a wide range of tools available to ensure everything works properly, efficiently and safely. One of these is the huddle, which is designed to improve communication quickly and simply, achieving team alignment and greater involvement in the process by everyone involved. "These huddles make it possible to share information in the hospital using previously- agreed indicators. Since they are well researched, it is easy to quickly identify whether a service is working properly and, if not, to take the necessary measures to achieve it," Ortiz added.

A simple methodology

What is a huddle? Basically, it is a short meeting, about 10 to 15 minutes long, bringing together representatives from each area involved in a given service. There is a meeting coordinator who orally reviews the indicators and asks for information from each participant. One by one, they share the indicators for their respective area, standing around a whiteboard on which the relevant information is written by hand. "Standing up makes the meeting more agile and quicker. And writing by hand has been shown to involve the information provider much more. In the end, what we achieve through all this is to empower the whole team and achieve greater involvement in all processes," Susana Ortiz continued. For the huddle to work, it requires a lot of prior work. It is important for the indicators to be clear, for key people with decision-making power to attend the meeting and, obviously, to have a well- defined objective. "Previously, everyone had their own information and did not know what was going on in other areas or departments of the hospital. So we sometimes spent the whole morning shouting continuously from one area to another, with all the timewasting that entailed and the possibility of errors arising when exchanging information. We lacked the cross-cutting vision we now have with the huddle," the Head of Processes added.

So, by using this tool, we can improve team coordination and communication at the hospital, creating better awareness of the situation and detecting problems more quickly. They can even anticipate and propose solutions, thus achieving efficient and sustainable day- to-day adaptation.

It also makes the professionals more proactive.

Progressive implementation at SJD

The first huddles were launched in 2018. These included the pediatric hospitalisation huddle, bed monitoring and emergency department monitoring. Since then, more and more have been added, rising from 6 in the first year to 23 in 2022. "At the beginning, the process team approached the professionals who we thought could make the most of this tool and suggested they use it. Now, seeing the success we have achieved, it is the professionals who come to us to ask for new huddles," said Susana Ortiz.

There are currently three levels at SJD Barcelona Children's Hospital. At the first level, on a daily basis, there are the basic clinical, care and ordering huddles. Then there is a second level, the Care Operations Group huddle. This is a weekly meeting of representatives from different huddles in the areas of global indicators and complex actions. Lastly, there is the weekly steering committee meeting with the hospital managers.

Do they really work well?

Implementing a new tool also requires an evaluation process to determine whether it is properly fulfilling the function for which it was designed. So SJD Barcelona Children's Hospital has carried out a survey among the professionals in the various huddles, which produced very positive results. 89.7% of those surveyed see it as a tool that improves internal communication. 89.7% think it has improved team coordination. 82.8% believe it has helped to anticipate problems. And 79.3% say it has had an impact on the safety culture. ■

INTERVIEW: JOAN COMELLA | Director of Innovation, Research and Knowledge Management at SJD Barcelona Children's Hospital and Director of the SJD Research Institute

Knowledge generation, research and innovation are essential to provide solutions for our patients"

A year ago, Joan Comella joined SJD Barcelona Children's Hospital as Head of Research and Innovation after 13 years as Head of Research at the Vall d'Hebron Campus. We asked him how he is handling this change and about his experience of this new role.

Joan Comella: I have joined SJD Barcelona Children's Hospital with all the enthusiasm of a child — he said emphatically.

Paidhos: What was your previous job at Vall d'Hebron like? Was there anything left to do there?

Joan Comella (J.C.): I have only words of gratitude for Vall d'Hebron and for all the people I worked shoulder to shoulder with for 13 years to give Vall d'Hebron the international relevance and standing it deserves. Now, with the feeling of a job well done, the only thorn in my side is not fulfilling the dream of witnessing the inauguration of the new research building. Creating this new building involved a lot of work by many people. Finally, circumstances aligned that enabled us to make the government understand that the research being done at the VH Campus —specifically at VHIR— deserved suitable high- quality facilities such as those being planned. I'm looking forward to seeing it finished.

Paidhos: Before you were at Vall d'Hebron you were already involved in research and management ...

J.C.: I am very critical of reality, so when I am asked to lend a hand with management structures, I feel it is only consistent to get involved. I feel I have to do it. And that's how I ended up working with the University of Lleida as vice-rector for research and the third cycle.

I like to contribute to making things happen, but not to be the star of the show. If we were running a restaurant, I would be more of a chef than a waiter, probably due to my shyness. I don't like public or media exposure. I understand that it is a responsibility that goes with the position and I accept it, but I don't like it. I also think that strength lies in teams, not in individuals.

Paidhos: And following that career path, how is the switch to SJD going?

J.C.: This stage at SJD is the third great professional leap I have taken. I hope it will be my last. It is a great challenge and I think it is the best place to do it, because it is a project based on values, full of purpose and intention.

Paidhos: You first became Director of Innovation and then Director of the SJD Research Institute (IRSJD). Why two senior management positions?

J.C.: For some time, the SJD management had been preparing for someone to take the baton from Jaume Pérez Payarols, who had a brilliant and admirable career. He led the hospital's research and innovation to where it is today. The challenge he has left on the table with research and innovation, which I am taking up, is an ambitious one. Thankfully, Pérez Payarols will remain in charge of teaching and training, which is of enormous value to the institution.

In this new stage, a profile with more of a scientific and research background rather than innovation was sought, specifically in order to be able to combine and promote the two areas with the same capability. Just as I was joining SJD, Francesc Palau, who has done excellent work as director of the SJD Research Institute, decided to end that stage of his career and return as head of his research group and the genetic diagnosis aspect. So I put myself forward in the public application process which, as a process takes a certain amount of time, in contrast to the position of Director of Research, which is a managerial post and position of trust in the general management, so the appointment was direct, very quick and immediate. It now makes particular sense to strengthen this area of research under the umbrella of a single department, as SJD has been included among the Catalan Government's CERCA centres.

Paidhos: You have now completed your first 6 months there. What does the institution look like from the inside? How did you imagine it and what has it actually been like?

J.C.: On an emotional level, I was much more surprised than I expected at how closely the values are aligned with reality. I have felt very welcome and supported by everyone. Hospitality is at the core of the organisation's DNA. At SJD you feel the organisation's true purpose, and you are part of it. You feel it all the time, everywhere, and you work to give children hope for their problem. Patients and families really come first for the organisation, to the extent that they are so much a part of the centre that they make day-to-day decisions. For example, regarding the design of rooms and research objectives and how this will be carried out. Kids Barcelona is another example: the children themselves take part in designing our innovation and research processes.

Paidhos: ... and at the professional level?

J.C.: I have been surprised by the great project that is the Únicas network and the hospital's capacity for transformation. How it has evolved from a charity hospital into an ultra-specialised, highly complex hospital, awarded most of the accreditations of excellence, both Catalan and Spanish, as well as European, accompanied by a strong academic, research and innovation component.

We are aware of what is expected of us. When you are at the head of a leading institution, you know that you are the one whose role is to provide solutions. SJD receives all the pathologies that have not been resolved by other more basic centres ... In a way, here we can see the failure of medicine. You are aware of the limits, and you understand that providing solutions will necessarily require the generation of knowledge, research and innovation.

Paidhos: What about this knowledge generation; how does it have to be done?

"Our professionals have to be researchers and pioneers"

J.C.: Knowledge generation has to be done first with our own professionals, who are researchers and pioneers. But we must not forget the added value of creating and participating in scientific networks and collaboration agreements. One of my greatest challenges right now is to create alliances with universities and centres in our area that are global benchmarks, and to seek solutions to unmet medical needs together. There are three ways of doing leading research: investing by capturing and rewarding talent; implementing an academy policy by promoting teaching and internal training to create a school, fostering this talent with involved professionals with future prospects; and the third is to share talent by forming alliances. Are they mutually exclusive? No. All three have to be done, because they complement one another and go at different paces. One of the challenges I clearly face is to make research part of resident training and to make this an incentive for them to come to SJD.

Paidhos: Earlier you talked about "purpose"... why?

J.C.: To provide solutions where there currently are none. In all areas, but particularly in the area of rare diseases, where the industry does not see a market for investment because there is a limited return. This is the uniqueness that we have at SJD with rare diseases. There are two areas that are very relevant but at the same time disappointing: one is diagnosis and the other is treatment. On the diagnostic side there are no records, so we never have a clear reference of the incidence of these diseases. We estimate that around 50% of patients are undiagnosed and 25% go from centre to centre for an average of almost 4 years before they find an expert diagnosis. The effort here is to reduce the number of undiagnosed patients from 50% to 20% and cut the diagnosis time from 4 years to no more than one year.

Joan Comella with Fátima Nuñez, assistant to the Director of Innovation, Research and Knowledge Management

Paidhos: And what is the solution?

J.C.: This will necessarily involve new analysis capabilities, not only genomics, but also metabolomics and imaging, and being able to integrate all this data and take advantage of expert systems to improve diagnostics.

The other major challenge involves new treatments. Many of the treatments for these diseases are substitutes; they do not actually cure the disease. The treatments we see on the horizon are more sophisticated and personalised. These patients need advanced, emerging therapies. Not just CAR-T treatments, which are already well integrated. We are also making a great commitment to gene therapy, brain and magnetic stimulation, new medical devices, and exoskeletons, among others. Here we must clearly focus on innovation and medical engineering. In short, research, research and research.

Paidhos: What does the Sant Joan de Déu Health Park in Sant Boi contribute?

J.C.: In the case of the health park, the solution is the same: research. Research and innovation must also be an important aspect for all professionals working in the field. So there is a key person, Josep Maria Haro, the deputy director of the Research Institute who heads adult psychiatry. I would also like to mention the importance of nursing and its role in all areas of SJD research. Nursing teams are key in healthcare practice, but also in clinical research. They are the ones who support patients on a daily basis, who are with them every hour and every day. That is why we are convinced that they have a role in research too, especially in clinical trials. The new nursing should be empowered to do clinical research, as is already the case in many English-speaking countries.

Paidhos: And what has the change from a generalist multi-specialist environment to a children- focused environment involved?

J.C.: Well, a lot of things have changed. Pediatric diseases are associated with development and there is a pediatric pathology that you don't see in a general hospital. Children are 20% of the current population but they are 100% of the future population. It is a very unique population that we must take care of. We have an obligation to give them a future with all the solutions we can offer them.

Another major difference is the management of causality. It is a lottery and we have to make uncommon things visible. Just because you are unfortunate enough to have a minority disease, that does not mean society should be less supportive than if you suffer a stroke or cancer, which can happen to anyone. So whether through civil society or by whatever other means, we must go where the interests of the pharmaceutical companies often do not reach. In this sense, SJD is an extraordinary example of civil society's involvement.

Paidhos: SJD is spearheading this involvement of society. Isn't this a failure of the public system?

J.C.: It is not the failure of the public system, but a success of civil society as part of the solution.

One tangible and impeccable example of this success is Pediatric Cancer Center Barcelona, because of the involvement of parents and children in its design, and because it is funded by civil society.

In a hospital such as this one, where there is such specialised healthcare for children, we also need a research environment to permanently seek solutions to these problems. We have an obligation to give hope and every opportunity to brave, struggling children. Once again, this must come from knowledge and the networking of such knowledge. All of this makes SJD a very special hospital, despite the fact that the model exists elsewhere, especially in the USA. This makes Barcelona a privileged region.

Paidhos: Does this connect with SJD's vocation for international reach? Will it be led by research?

J.C.: Our relationship with US hospitals has always been very important and very fluid, especially at the level of the centre's management and the many professionals who have been trained in American hospitals. At the European level, a network is now being consolidated that should allow all of the structures to be strengthened. It should make it possible to apply for projects jointly, and reach out to the industry for rare diseases from a stronger position.

Together we can achieve volumes that cannot be achieved individually. This is the challenge that the Únicas network intends to tackle in Spain. I should also mention the ECHO (European Children's Hospitals Organisation) network at European level.

Paidhos: What is the first action you have taken as Director of Research and Innovation?

J.C.: (smiles) I have opted for prudence first and foremost. And I have made an effort to understand the organisation and to talk to people, to many people, but unfortunately not yet to all of them. I am very aware, in all humility, that I am joining a great project. I have come to a great hospital and I have come to help and keep promoting a great project. I have not come to revolutionise things.

I understand my leadership from the position of being facilitators. We are here to take care of the structure to aid the researchers' work as much as possible. Our job is to be ahead of the curve, to anticipate the difficulties, listen to problems, make the necessary changes to solve them, simplify the bureaucracy and, especially and at the same time, find funding or anticipate needs they do not yet have but will have, which have to be provided within the structure of the institution.

Paidhos: You have mentioned several times that talent management is an indispensable part of this knowledge. How do you manage it?

J.C.: A highly-complex hospital like SJD would not be one without its research and innovation department. The prestige is created by the professionals and the work they do. Being at the forefront of new treatments requires research and innovation. The fact that professionals can carry out research projects is the added value, a kind of emotional remuneration. This new stage SJD Hospital is facing of expanding its international reach and expert leadership in rare diseases necessarily involves strengths in the field of research. And that is provided by such talent.

Talent is many things and you have to be able to attract it, nurture it and make it grow. You have to explicitly recognise this and free up care time so it can be done. We have extraordinary professionals and we have to make the most of them and know how to manage them. The institution must do its utmost to recognise and grow this talent, as well as retain it.

Paidhos: We cannot end the interview without talking about one of SJD's great strengths: outreach, especially in terms of transferring research to society.

J.C.: It is something I really admire! I have found the institution to have a spectacular ability to get the message across to the population in many areas because we have a responsibility always to find the best way to convey to society what it needs to know and when it needs to know it. We cannot simply keep knowledge to ourselves. We have to convey it to society in order to involve and support it. We then receive a great return, as society responds. It is the best stimulus and the best indicator.

We not only want to cure, we also want to provide answers and do our bit to encourage people to have a scientific vocation, as part of this vision of contributing to this knowledge.

Paidhos: And where does Dr Joan Comella's vocation come from?

J.C.: I didn't really have much of a "medical" vocation. I was more of a naturalist than a scientist. I come from a small village and a family in the Lleida countryside. I grew up happy in full contact with nature and fields of orchards. I went to Lleida to study medicine, but I did not have much of a vocation. My life was changed by the person who would later become my thesis supervisor, Josep Esquerda. He was a histology lecturer who fascinated me and introduced me to the world of the developing nervous system, far beyond what was in the second-year syllabus. I had the opportunity to learn about the work of Rita Levi- Montalcini, who studied neuronal trophic factors. Many years later, when she had been awarded the Nobel Prize, my whole family was able to meet her at her flat in Rome. We worked in this field and tried to study why motor neurons lived or died. I went from not having a vocation to having a what and a why. I still work in the field of neurodegenerative diseases and it is in large part thanks to her.

Paidhos: Going back to the country boy who ran through the fields of Lleida ... Is there anything you would say now to that boy? (He pauses and I get goose bums)

J.C.: Yes! Of course I would. I would tell him to do the same again. I acquired values that are fundamental to me, such as friendship, honesty, trying to do good. I learned these values mainly at home and they made me who I am and taught me the way I see life. I am happy and proud to be from the countryside!

Paidhos: And when you are not managing, doing research or connecting with your inner child, what do you like to do?

J.C.: I like many things, but I particularly like travelling with my family. Another of my passions is dance and music. But what reconnects me with my body is running. I can't do without that. It's almost like meditating. I try to run every day for 30 minutes and if I can I run half marathons. I started running late at around 50. But it is never too late. Running makes me feel very good vitally. You run with yourself and against yourself. Not to compete. ■

"To do leading research, you have to invest in talent, have a good academy policy and form alliances"

Better pain management in hospitals is possible

In 2023, the Pain Group of the SJD Barcelona Children's Hospital set up the pain map for the inpatient wards of the hospital with the aim of helping the nursing team gain an overall view of their patients' pain. This was done to create a pain-free hospital and to further humanise healthcare.

Pain has been associated with healthcare for a long time. It is one of the main symptoms of many pathologies, and many treatments and surgeries also end up causing it. For this reason, it was assumed to be just another burden for the patient and was not one of the main concerns in healthcare. Not much effort was devoted to fighting it. Fortunately, today, this situation is now changing.

We now understand that pain does not have to be present and that the patient's suffering is not only not harmless but, in many cases, it can even worsen outcomes. Many healthcare facilities are now trying to fight pain, and the SJD Barcelona Children's Hospital is one of the most active in this regard, with a new Pain Group in place since 2019,

32 the successor to the Pain Team.

One of the Pain Team's main objectives was to make pain the fifth vital constant and, as such, assess and record it in the clinical history so that all healthcare staff achieve better pain control.

A tool for better control

Being able to monitor the condition of hospitalised patients quickly, simply, and effectively is essential for pain management. This is how the pain map came about. 'It consists of a tool that includes all the beds on inpatient wards. Thanks to a simple colour coding system, we can see the status of each of these beds in terms of pain management for the patient,'

Mònica Rebordosa, a pain specialist nurse and one of the persons in charge of developing the tool, explains.

This pain map also shows this entire situation in real-time, based on the Computerised Clinical History records. To simplify it and make it more visual, it is colour-coded and provides information about each patient admitted to the ward: green for patients without pain, orange for patients with mild pain and red for those with severe pain. There is also a fourth colour, purple around the bed, which shows those patients who have not undergone a pain assessment according to the protocol established for each case.

'Thanks to this map, developed by colleagues Ricard Casadevall and Jaume Busquets, we have managed to raise awareness among all professionals of the importance of pain management, making better control of patients possible and helping to detect patients with unmanaged pain,' adds Rebordosa, who goes on to

Laura Monfort and Mònica Rebordosa, responsible for the pain map

explain how this tool, in addition to identifying those patients with unmanaged pain, also serves to prioritise assistance to those who need it most.

Progressive implementation

The pain map was first piloted in March 2022 on the wards on the tenth floor of the SJD Barcelona Children's Hospital and the seventh floor maternity ward. After its great results, it was implemented in the rest of the inpatient units and at the SJD Pediatric Cancer Center Barcelona in February 2023, making the SJD Barcelona Children's Hospital one of the pioneers in implementing this type of tool in Spain.

Given the vital help that this map has provided for the more adequate management of patients' pain, we are also thinking about its possible adaptation and use in other areas of the hospital, such as the Intensive Care Unit. Although more extensive monitoring is already in place there, it could also prove helpful.

Humanisation of healthcare

Healthcare facilities are putting more and more effort into humanising healthcare. Achieving a cure is no longer enough. We are also seeking to make the process as pleasant as possible for the patient. 'There is no need to suffer pain, or if it is present, we have enough tools to minimise it. Furthermore, several studies have shown that by controlling pain, the number of days of hospitalisation can be reduced, and this has an important impact on the sustainability of the healthcare system,' adds Mónica Rebordosa.

This humanisation is particularly relevant for pediatric patients who, thanks to this better pain management, are able to understand that the hospital is their friend. 'And if families see that child patients are not suffering, we also achieve an important reduction in the burden of anxiety that they already have when faced with the extremely stressful situation of seeing a young child hospitalised,' the pain specialist says. ■

Pioneering project for the prevention and promotion of mental health of adolescents

SJD Barcelona Children's Hospital and Zurich Spain, through the Z Zurich Foundation, have recently presented the Henka programme: Growing in emotional wellbeing, an inclusive and universal project that is aimed at the entire educational community and that focuses on adolescents.

In Catalonia, the programme is supported by the Ministries of Education and Health (Spain) and is aligned with the strategies of the Mental Health and Addictions Master Plan to promote the promotion and prevention of mental health in the child and youth population. The objective of Henka, a Japanese word that means 'transformation', is for young people to face adversity in a healthy way, with tools that foster the development of resilience capabilities as a protective factor. This means a reduction in both the risk of suffering from a mental health disorder and the negative impact of many problems that adversely affect the wellbeing of adolescents.

Those responsible for the Henka programme hope that it will positively impact more than half a million people, especially students, but also family members, teachers and other groups who contribute to

the mental health of adolescents

3. 4 being a priority in educational environments. Some 450 schools will be involved in this initiative, more than 70 of which are schools with vulnerable backgrounds.

The programme aims for a holistic approach in secondary schools starting with children aged 12. This is considered an evolutionary period characterised by major neuroplasticity and when the adolescent has a great capacity to learn, a fact that is key to working on prevention. Their families, teachers and other socialisation agents will receive training from SJD Barcelona Children's Hospital specialists in promoting and developing resilience skills so that they can implement the programme autonomously in an educational context.

Once the activities for acquisition of these skills have been implemented (socio-emotional learning workshops, learning coping strategies, etc.), adolescents and caregivers will be empowered to evaluate their experience and based on this, and in their particular context, they will be able to access the tools and recommendations to develop an action plan that allows learning to be incorporated into the culture of the facilities, so that emotional wellbeing becomes one of the main axes of the educational project.

This new project represents an advance in the social programmes of Zurich Spain, with the support of the Z Zurich Foundation, aimed at supporting those communities of young people from vulnerable environments to promote social equity and diversity in the future of adolescents.

'In our social action, we prioritise vulnerable groups, especially young people and women, and we take care of the planet, and that is why we have to be an example of commitment and become activists. This means taking action, carrying out projects that improve people's lives, that create a fairer world, and working towards a sustainable future,' says Cristina Gomis, CSR director of Zurich Spain. 'Carrying out this project with the help of SJD Barcelona Children's Hospital gives us the confidence and experience of a team that works by and for young people.'

Sofyen Khalfaoui, head of the Mental Wellbeing Improvement Programme at the Z Zurich Foundation, says that 'the ambition of the Henka programme is unprecedented in Spain and we firmly believe that it will have a positive and lasting impact on youth, as well as in the rest of society: its community and innovative approach can sustainably change the way adolescents and their educational environment talk about emotional wellbeing, effectively manage stress and allow them to reach their full potential.'

Impact on society and individuals

So that the initiative represents a transformation in the way in which emotional discomfort and mental health problems of adolescents and young people are addressed at the level of the entire community, the project will include the organisation of spaces for reflection, debate and exchange of knowledge with the participation of representatives of the public administration, specialists in child and adolescent development and mental health, pedagogy and emotional education, young people, social agents and individuals in general. These will be biennial; the first will be held in Barcelona in 2024 and the second in Madrid in 2026.

With this same objective, awareness campaigns will be carried out based on the documentary series #Jo-Ho-CanvioTot, and the SOM Mental Health 360 platform will be promoted, a project that was launched three years ago and is already a reference in mental health in Spain and Latin America with more than 40,000 monthly visits.

According to Anna Sintes Estévez, a clinical psychologist at the SJD Barcelona Children's Hospital and director of the Henka programme, 'given the current situation, strategies must be developed to promote mental health and prevent mental disorders in different contexts and levels, according to the degree of distress.' Furthermore, she says that 'by emphasising the promotion of protective factors and early detection of risk, the mental health of all adolescents can be improved, without introducing specialised interventions aimed at specific populations into the natural environment of socialisation.'

On the other hand, in her opinion, the interventions have to be focussed on the individual and their cognitive, emotional, and social development process, emphasising the autonomy, participation and responsibility of adolescents and their families.

Resilience as a construct

Specialists in child and youth development have identified resilience as a construct, with scientific validity and encompassing a whole series of personal tools (socio-emotional and cognitive capabilities) that determine the level of personal vulnerability to difficulties and life events that generate imbalance and distress.

All international programmes aimed at promoting mental health in children and young people are currently based on the concept of resilience as the backbone to improve social relationships, academic performance, participation, and social integration. In short, greater resilience is related to less psychological vulnerability and, therefore, to a healthier attitude and more balanced perspective.

An inclusive and universal project

The project promoted by SJD Barcelona Children's Hospital and the Z Zurich Foundation is inclusive and universal. It is aimed at the entire educational community and focuses on adolescents in general. It does not exclude any young person since it promotes the development of general socio-emotional skills that improve the coping capacity of all adolescents, regardless of the current state of mental health. The family is essential, as is the educational community, because it is the environment where the child develops. The programme has been co-created with teachers and other professionals in the world of education and is particularly considerate of schools in vulnerable environments, where it will be implemented with additional resources.

Those responsible for Henka proceed from the systematic, exhaustive, and critical review of programmes to promote resilience that have already been successfully applied and validated in other countries. This means components have been selected that have shown greatest effectiveness and applicability in our cultural context.

The training, accompaniment and subsequent transfer programme include interventions such as workshops or group dynamics, to be carried out in classrooms and with families, but including recreational and socialisation contexts in general is also planned through the incorporation of resources for integration, awareness, and social impact. ■

Teachers at a promotion and development of resilience skills training session

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