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20 YEARS

MY CHILD
MATTERS



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Twenty Years of Making Children Matter

Twenty years ago, **My Child Matters (MCM)**, an initiative of **Foundation S**, was launched with a simple conviction: that where a child is born should not determine whether they survive cancer. Two decades later, that idea has become a living, global network of people, places, and practices, and this special issue of **CancerWorld** is shaped entirely by its impact.

Across these pages, we mark **20 years of My Child Matters** not with celebration alone, but with stories. Stories of children who completed treatment because transport was paid for. Of families who stayed close to hospitals because a home was built for them. Of nurses, doctors, data scientists, parents, and survivors who turned local need into lasting change.

The journeys gathered here span continents and contexts. From **Ukraine**, where professional training continues despite war, to **Nepal**, where shared-care networks allow children to receive treatment closer to home. From **Paraguay**, where My Child Matters helped seed a national transformation in pediatric oncology, to **Kenya, Uganda, Malawi, Bolivia, Indonesia, Pakistan, Colombia, Peru**, and across **Latin America, Africa**, and **Asia**, these stories show what sustained commitment looks like on the ground.

What unites these diverse narratives is not a single model or intervention, but a shared philosophy: **progress is only meaningful when it reaches the child**. Over twenty years, My Child Matters has shown that improving childhood cancer outcomes is not only about drugs or protocols, but about trust, dignity, proximity, training, data, and long-term partnership.

This special issue is our way of honoring that journey, not as a retrospective, but as a living record of impact. Because these stories are not endpoints. They are proof that when commitment is measured in decades, systems change, survival improves, and children are given what they have always deserved: a **fair chance at life**.

Yeva Margaryan, Managing Editor, CancerWorld

NOT FOR SALE





Twenty years ago, the **My Child Matters (MCM)** program was launched by the Sanofi Espoir Foundation (today Foundation S). This program aimed to improve access to treatment for children and their families in low and middle-income countries (LMIC). Twenty years later, this program has supported more than 280,000 children in LMIC, and its impact has been one of the most significant globally in the field of paediatric oncology. The My Child Matters program is addressing practical issues experienced by clinicians, nurses and health care providers in their daily commitment to children with cancer. Working on the ground is the essence of this program that has been transformative around the globe. Projects granted over the last 20 years involved early diagnosis, capacity building, treatment abandonment, supportive care, palliative care, psychological support, cancer registries, and telemedicine, amongst others. A special celebration took place on October 20th, 2025, in Amsterdam, during the Annual Meeting of the International Society of Paediatric Oncology. This was a very emotional moment, during which we looked back at these two amazing decades, shared stories of MCM's achievements and acknowledged the wonderful leadership of Dr. Anne Gagnepain and Dr. Isabelle Villadary, who made the MCM program such a unique initiative.

In this special issue, you are invited to discover the impact of My Child Matters in Colombia, Paraguay, Tanzania, Ukraine, Bolivia, and Sub-Saharan Africa. You will also learn about specific programs such as the *My Child Matters Nursing Awards*, *The Teleo Initiative* or the *#CheckUpAYA*, that addresses the needs of adolescents and young adults with cancer in South America. Last but not least is the *Home Away from Home* initiative, launched 2 years ago in collaboration with CCI, Childhood Cancer International, with two wonderful testimonies from Cecilia Quirogas and Alejandra Mendes. All these stories are moving and inspiring. They show that together, we can make a difference. Please enjoy the reading; some stories may bring tears to your eyes. If this is the case, the objective of this special issue of CancerWorld will be met!

Wishing you a peaceful Holiday Season,

Eric Bouffet, Chair of the My Child Matters Expert Committee



**Isabelle
Villadary**

When Each Child Matters

By Gevorg Tamamyan

When Isabelle Villadary speaks about her work, one immediately senses a rare combination of clarity, pragmatism, and compassion. Today, she leads the childhood cancer programs at **Foundation S – The Sanofi Collective**, steering one of the most impactful global initiatives in pediatric oncology: My Child Matters.

Her journey, however, was not a straight line to pediatric cancer. It was a trajectory shaped by a passion for data, a commitment to populations rather than only individuals, and a belief that the greatest health solutions emerge when public, private, and community actors work together.

From Medicine to **Global** Health

"I did medicine because I wanted to do something for others," she recalls. "When you are very young, you want to save lives."

Early in her career, she realized that population-level health could achieve broader impact than individual clinical care. "I saw that the impact could be bigger if you take care of a population rather than one patient," she explains. That perspective drew her toward global health, where she worked

on malaria prevention campaigns in Africa and France.

Along the way, she discovered epidemiology — and fell in love with it. "**I love data.** I love demonstrating the impact of an action," she says. For Isabelle, data are not dry statistics, but tools of empowerment: "Pragmatic data collection and dissemination can bring real added value for decision makers."

It was this combination — medicine, global health, epidemiology, and pragmatism — that set the foundation for her later leadership in pediatric oncology.

A Path Through Public and Private

Her professional path began in France's public health agencies, advising decision-makers on HIV, tuberculosis, and other pressing issues. "What I loved was being very close to decision makers, but still providing them the data to take the right decisions," she says.

She later moved into market access, leading evaluations of medicines and vaccines for reimbursement. "That was also very pragmatic," she recalls. "But then I realized that all the

data I was working on came from the private sector. I was curious to understand how that world functioned."

Curiosity led her to join Sanofi, where she worked for several years before returning to her first passion — global health — through Foundation S. "When I discovered My Child Matters, I was already impressed by the impact of the program," she says. "I wanted to bring my value, my energy, and my engagement to make it even bigger."

Seeing the World in Shades of Gray

One of Isabelle Villadary's personal philosophies is that progress is built on dialogue between different perspectives. "I see the world as gray," she says. "There are no people who are completely right or completely wrong. It is very good to put around the same table people with different perspectives — public, private, NGOs, decision makers — and try to find solutions together."

This philosophy has defined her leadership style. She emphasizes authenticity, curiosity, and courage. "**Curiosity is the driver,**" she insists. "Being scared only keeps you in your comfort zone."

Mentorship Through Curiosity

When asked about mentors, Isabelle does not single out a famous figure but rather a way of approaching others. "My mentors were always the people I was curious about," she explains. "I would go to them and say: I want to understand what you are doing. Can you explain it to me?"

Sometimes this meant admitting fear. "When I moved from public to private, I told people, I am afraid. I don't know how it works in your sector. Can you help me? Those people became my mentors."

For her, mentorship is not about hierarchy but about openness. "It is about asking the right people, listening actively, and letting curiosity guide you forward."

To Listen, To Trust, and To Support

This year marks the 20th anniversary of My Child Matters, the flagship childhood cancer initiative of Foundation S. Isabelle Villadary joined the program with deep respect for its history and a determination to shape its future.

She describes the program's genesis with clarity: "Every year, 400,000 children face a diagnosis of cancer. Eighty

percent of them live in low- and middle-income countries. For the six cancers targeted by WHO, survival is more than 80 percent in high-income countries — but less than 20 percent in low-income countries. That means for these children, the reason for dying is less the cancer itself than the place where they live."

That injustice became the driving force. "The gap is linked to factors like access to hospitals, training of healthcare professionals, family support, and palliative care. These are things we can act on. And those who know what to do are the local teams. Our role is to listen, to trust, and to support them."

"We think globally, but we act locally."

Under her leadership, My Child Matters has expanded its reach. "We now support more than **184 projects in 87 countries, training over 58,000 healthcare professionals and impacting close to 300,000 children,**" she says.

But Isabelle stresses that behind every global number are local stories: "Each project adds its data to the global picture. The same challenge — like treatment abandonment — may require a very different approach in Bolivia compared to Malawi. Local teams know best. We trust them, and we help connect them with mentors and experts."

For her, this is what makes My Child Matters unique. "We think globally, but we act locally. And that is where the real impact happens."

That One Child Matters...

Isabelle is quick to remind us that while numbers matter, stories bring meaning. "I love numbers," she admits with a smile. "However, stories are critical as well. Behind every data point, there is a child, a family, a life."

She offers an example: early diagnosis projects. "To detect new patients, you may need to reach thousands of people just to find one child. That means huge preparation, many stakeholders, and at the end of the day, perhaps only one diagnosis earlier than it would have been. But that one child matters."

By contrast, palliative care projects may touch fewer children but transform survival outcomes. "So numbers alone never tell the full story," she explains. "Data is critical, but it must always be complemented with stories and with what is behind the data."

Her insistence on publishing results is equally strong.

"Generating data is not enough. It is critical to publish it. Publications bring sustainability, reputation to local teams, and knowledge to the scientific community. They inspire others to duplicate, adapt, or move to the next stage."

Today, My Child Matters boasts more than 300 scientific publications — an extraordinary contribution from teams across the world.

Recognizing Local Heroes

When congratulated on these results, Isabelle Villadary deflects credit: "The first people to acknowledge are the teams on the ground. I may be the one interviewed today, but there is nothing without them. They are the ones taking care of children, speaking with parents, running the projects. Each publication belongs to them. Foundation S is just catalyzing their efforts."

Her vision for the future is to bring these data and stories together in ways that influence policy. **"We want decision-makers to realize that very small actions from their side can provide huge added value for childhood cancer in their country,"** she says. "That is the next step."

Success Through Collective Work

For Isabelle, the heart of My Child Matters is collective work. "One of the key success factors is the collective dimension," she says firmly. She points to the example of pediatric oncology congresses where oncologists, nurses, parents' groups, and professionals from both high- and low-income countries come together.

"This spirit of working collectively — across disciplines, across countries, across income levels — is a lesson learned. And it is a success factor we have adopted within My Child Matters."

Low- and middle-income countries, she emphasizes, are not only beneficiaries but contributors. "They bring added value for everyone in terms of data generation and healthcare strengthening. They must have a voice."

A Holistic and Local Approach

Another strength of the program is its flexibility. "We do not have a model that we apply everywhere," Isabelle explains. "Local teams tell us: In my country, I will do it this way. And we acknowledge and support them."

She points to the problem of treatment abandonment.

In some countries, the solution has been to provide accommodation near hospitals — "home away from home" initiatives. In others, direct financial support to families proved more effective. "The objective is the same, but the design is completely different," she says. "That is part of the DNA of My Child Matters: trust local teams. They know what will work."

Advice for the Next Generation

Asked what advice she would give young professionals, Isabelle reflects: "Personal success comes from being passionate about what you are doing. Without passion, it is very hard to stand in this field."

She also emphasizes the importance of collaboration. "Work collectively. Build networks. Because everyone has difficult moments, and when you share with others, your energy comes back. **Never stay alone.**"

Looking Ahead

Isabelle Villadary sees the future of childhood cancer control as a continuum between philanthropy, healthcare systems, and research. At Sanofi, that bridge includes colleagues like researcher Iris Valtingoer, who is leading programs on bridging the gap between adult and pediatric trials and catalyzing research for cancers that still lack treatments.

"She is catalyzing a lot of efforts," Isabelle says. "We share the same objective, but with different approaches — philanthropy on one side, research and R&D on the other. Together, we move forward."

Finally, she stresses the importance of amplifying voices from the Global South. "People in Africa, Latin America, Asia — they often have less opportunity to be heard. But they bring lessons learned for everyone. Giving them visibility is critical."

A Program That Lives Up to Its Name

Twenty years on, My Child Matters has grown from a vision to a global force — uniting hundreds of projects, thousands of professionals, and nearly 300,000 children. But Isabelle Villadary insists the essence is not in numbers, but in values: pragmatism, passion, collaboration, and trust in local leadership.

As she concludes: **"Behind every project, every statistic, there is a child. And each child matters."**

Zero Abandonment from Start to Finish



Cash Transfers to Reduce Treatment Abandonment and **Improve Childhood Cancer** Survival in Sub-Saharan Africa.

By Trijn Israels

In sub-Saharan Africa, where healthcare resources are scarce and poverty often defines the limits of possibility, many children with cancer still die not because they are not diagnosed or their disease is incurable, but because their treatment is not completed.

Treatment abandonment — when cancer therapy is not started, stopped, or interrupted for more than four weeks for non-medical reasons — remains the most common cause of treatment failure in many parts of this region. In some hospitals, up to half of children never finish treatment. Families' inability to afford the out-of-pocket costs associated with treatment —transport, food, accommodation, sometimes drugs—remains a major contributor. This is a tragedy that can and must be prevented.

The vision of the Zero Abandonment from Start to Finish

programme is simple yet transformative: to prevent treatment abandonment—or reduce it to below 10%—among children with common and curable cancers in sub-Saharan Africa. Successful implementation of simple, low-cost, comprehensive interventions can achieve this and will potentially have a huge impact on survival.

'Treatment Abandonment' - A **Misleading** Term

The phrase "*treatment abandonment*" can be misleading. It may suggest an 'active choice' from parents to 'reject' treatment which is not the case. Across Africa, like everywhere in the world, parents do everything they can and more for their child to survive. They sell livestock, borrow money, sleep on hospital floors, and spend months away

from home in the hope that their child will get better and survive. But poverty forces impossible choices. Imagine a mother, already for weeks in the hospital with her child who is slowly responding to treatment. Her other children are in the village, hundreds of kilometres away and it is planting season, the maize seeds need to go in to hopefully have food security later in the year. Every day away from home means more debt and food shortage. When parents leave the hospital, it is not abandonment, it follows an impossible choice in a situation of desperation.

The **Roots** of the 'Zero Abandonment' Programme

In 2019, a 'Zero Abandonment' pilot project provided cash transfers to families of children with cancer in Blantyre, Malawi. **Covering all transport costs, the intervention cost an average of €200 per family and reduced treatment abandonment from 19% to 7% ($p < 0.001$).** It proved highly cost-effective according to established criteria and sustainable—five years later, abandonment rates remained below 10%, facilitated by local leadership and funding support from a different donor.

Encouraged by this success, the project expanded into a multi-country initiative coordinated by the **CANCaRe Africa network**. Families of children newly diagnosed with common and curable cancers receive about €200, distributed in three instalments across the treatment period. A key principle is trust: funds are unconditional. Parents decide how to use them—for transport, food, medicines, or school fees. There are no restrictions because parents know best what their families need to complete treatment. Early data show strong adoption and reach, with significant reductions in abandonment predicted across participating hospitals.

Beyond Money: **Empowerment and Dignity**

These cash transfers are not payments for compliance, nor acts of charity. They are acts of partnership—acknowledging that poverty drives non-completion of treatment. By relieving financial pressure, the programme allows parents to focus on what matters most: caring for their child. It also strengthens trust between families and health workers. Every transfer sends a clear message of hope: *we trust that your child can recover, and we are committed to supporting you throughout the treatment process.*

Generating Evidence with Purpose

The programme uses and generates local evidence with

purpose. Local evidence is key in the 'positive cycle' leading from available evidence to advocacy to raising funds to implementing interventions (funds), evaluating impact, and generating new evidence.

The pilot programme in Malawi implementing cash transfers demonstrated effectiveness, cost-effectiveness, and sustainability. Another multi-centre CANCaRe Africa among children with common and curable cancers showed that treatment abandonment was 24% and event-free survival only 40%. **If abandonment were prevented, survival rates could potentially rise to 60%.**

Building on these findings, the current multi-country programme is rigorously evaluating the impact of the intervention on treatment abandonment and survival. Preliminary results predict a significant decrease in abandonment and increase in survival.

The team also studies how best to deliver and sustain the programme, e.g. perceived barriers of adoption, reach and sustainability and how to adapt the implementation strategy across different hospitals and local contexts. The RE-AIM (reach, effectiveness, adoption, implementation, maintenance) and D4DS (design for dissemination and sustainability) implementation science frameworks are guiding these efforts.

We all build upon each other's efforts and achievements.

The programme expects to provide rigorous evidence of the effectiveness of unconditional cash transfers to significantly reduce treatment abandonment and increase survival of children with cancer in sub-Saharan Africa. Additionally, we aim to share lessons learned on how to implement such a programme. We hope that these contributions, together with contributions from many other parties and stakeholders will facilitate the further development and successful implementation and scaling of effective and sustainable interventions. We all build upon each other's efforts and achievements.

Conclusion

At its heart, **Zero Abandonment is about trust, dignity, and shared humanity.** It recognizes that every parent, everywhere, wants the same thing: a chance for their child to live.

The programme does not replace the need for strong health systems or universal health coverage, but it shows that small, thoughtful, and pragmatic interventions can make a significant difference and have a huge impact on survival when they address the real barriers families face to complete treatment. Every child deserves the chance to complete treatment. Every parent deserves support when doing the hardest thing imaginable: fighting for their child's life under impossible circumstances.



From Silence to Hope

Paraguay's Journey with Fundación Renaci and the My Child Matters Program by Foundation S

By Miguel Samudio

My name is **Miguel Samudio**, I'm from Asunción, Paraguay, and I currently serve as the **President of Fundación Renaci**, where I also lead the **Marketing and Communications Department**.

I am the youngest of three siblings and hold a degree in **Veterinary Science**, driven by my lifelong love for animals. Later, I earned an **MBA focused on Project Management**, as I've always been passionate about social impact and high-value initiatives. What inspires me most is connecting with people's stories, understanding how each person sees the world in their own unique way.

Both of my parents are **pediatricians**, and from a young age, I was fascinated by their dedication to children's health. My mother, **Dr. Angélica Samudio**, was the **first pediatric hemato-oncologist in Paraguay**, and I grew up witnessing her tireless commitment to improving childhood cancer care in our country, at a time when the reality was

very different from what it is today.

As a child, I often joined hospital activities, sharing snacks, spending time with young patients and their families, and seeing firsthand their needs and struggles. Those moments sparked something inside me, the desire to help, to create small but meaningful changes that could bring light to the lives of others.

Fifteen years ago, childhood cancer in Paraguay was an uphill battle. The **treatment abandonment rate exceeded 20%**, and survival rarely reached **30%**. Access to care was centralized in the capital, Asunción, and for many families from rural areas, reaching the hospital meant leaving everything behind, their homes, their work, and sometimes, their hope.

That's when I decided to dedicate myself fully to Fundación Renaci. My background in communication and marketing

became a bridge, I wanted to tell stories that transcended borders, to give visibility to those children and families who needed support, and to inspire more people to join our mission.

Fundación Renaci, became the heart of a national movement to transform pediatric oncology in Paraguay. Fifteen years ago, we started a powerful partnership with **My Child Matters**, a program by **Foundation S**, which became the turning point for childhood cancer care in our country.

Fundación Renaci with the partnership of My Child Matters by Foundation S, with the **Faculty of Medical Sciences (UNA)** and the **HOPE pediatric oncology team**, the initiative launched the first **four satellite clinics across Paraguay**. These clinics brought diagnosis and follow-up care closer to families, reducing the need to travel hundreds of kilometers to the capital. It was a milestone of equity and inclusion, a new chapter of access and dignity.

Through My Child Matters, Fundación Renaci helped establish a model of comprehensive care based not only on medical treatment but also on **psychosocial support, education, and empathy**. Families felt seen. Health professionals felt supported. And children began to have a real chance at survival.

Over time, the impact expanded. Fundación Renaci developed **national protocols**, trained **thousands of professionals** across the country, and built networks of collaboration between hospitals, universities, and the Ministry of Health.

In **2021**, after completing my master's degree, I had the honor of being appointed **President of Fundación Renaci**. Since then, we have continued to grow, guided by the same mission that inspired our beginning:

"To ensure that every child with cancer in Paraguay receives comprehensive, human, and equitable care, and that no family faces this journey alone."

In **2023**, we launched **TELENEC**, a national digital health network connecting pediatricians from 50 sites in all 17 regions of Paraguay with oncology specialists in real time. This innovation broke geographic barriers and strengthened professional mentorship nationwide.

In **2024**, we initiated **Paraguay's first Pediatric Palliative Care Program**, ensuring that even in the most difficult moments, children and families receive comfort, compassion, and accompaniment.

And in **2025**, we began one of our most meaningful initiatives: **the Survivorship Program**, dedicated to long-term follow-up and rehabilitation for children who have overcome cancer, a symbol of hope and continuity.

This same year, we proudly inaugurated the

Comprehensive Wellness Center for Children with Cancer, a space born from years of work and dreams. This center offers **psychological support, rehabilitation, palliative care, educational workshops, and digital telemedicine through TELENEC**. It represents our belief that care must go beyond hospital walls, it must embrace the child, the family, and the community.

Today, **treatment abandonment is 0%**, survival rates have risen to **over 75%**, and hundreds of families receive psychosocial and emotional support each year. More than **4,900 doctors, 1,600 nurses, and 2,600 parents** have been trained in early detection and comprehensive care.

Behind every number, there is a story of resilience, of a mother who dares to hope again, of a child who rings the "bell of victory" after completing treatment. Those stories are the reason we keep going.

The success of Fundación Renaci and My Child Matters was never built on infrastructure alone, but on people, on passion, teamwork, and belief. As we often say in Paraguay:

"Do not start with buildings or equipment. Start with people."

Through training, mentoring, and collaboration, we have created a sustainable model that is now part of Paraguay's healthcare identity.

The journey was not without challenges, medicine shortages, staff turnover, the COVID-19 pandemic, and digital gaps in rural areas tested our resilience. But the network we built stood firm, driven by trust and collective purpose.



As we celebrate **20 years of the My Child Matters program**, we look back with deep gratitude. Gratitude to **Foundation S** for believing in Paraguay, for walking beside us, and for helping us transform not only systems but lives.

What began as a project has become a **national movement**, one built on compassion, knowledge, and hope.

Because where a child is born should never determine their chance to survive cancer.

Development of **Paediatric Oncology** Shared Care Networks **in Nepal**

A Story from
World Child Cancer

By Domitille de La Gorce



When three-year-old Simran first began running fevers, her parents, Pradip and Bishnil, tried not to worry. She was their "miracle baby," as her mother calls her, born after many years of waiting, and the light of their small home near Pokhara. Her older brother, fourteen-year-old Suman, adored her. Life was simple, sometimes difficult, but full of quiet joy.

At their local health unit, doctors suspected a common infection and prescribed antibiotics. For a short time, the fevers eased, but they always returned. As Simran grew weaker, the family used their small savings to visit a private hospital in Pokhara. The doctor there noticed something unusual in her blood tests, something serious. He advised them to seek urgent examination at Kanti Children's Hospital in Kathmandu, Nepal's national specialist centre for childhood cancer.

That moment brought clarity but also fear. "We didn't know how we could manage," Pradip says quietly. "But she is our miracle baby. We had to try." At Kanti Children's Hospital, further tests confirmed what no parent wants to hear: Simran had T-cell acute lymphoblastic leukaemia (ALL), a fast-growing cancer of the blood. "We were terrified," says Bishnil. "We thought we would lose her."

The next three months were among the hardest the family had ever lived through. Simran underwent intensive chemotherapy. "It was very hard," says Pradip. "But we saw she was getting stronger."

Now, as Simran completes the first phase of therapy, her

family has received news that has changed everything: she can go back home for the maintenance stage of her treatment. This means her family can stay together, her father can work again, and she can still receive the care she needs.

"When we heard we could go home and continue treatment there, I cried," says Bishnil. "It means we can be with our son again. Pradip can earn money. And Simran can still get her medicine. We feel so much relief."

Simran's ability to do her maintenance treatment close to home has been made possible thanks to the financial support of **FOUNDATION S**, which has contributed to funding the ongoing development of a shared care network in Nepal. Through close collaboration between the Ministry of Health, WHO, World Child Cancer, and local partners, this network allows children to receive much of their cancer treatment and support at hospitals closer to home, rather than traveling long distances to the capital.

By strengthening local hospitals and connecting them with specialist centres, families like Simran's can stay together, reduce travel and financial hardship, and give their children a better chance to complete treatment and recover in the comfort of their own community.

As Simran holds her mother's hand, ready to travel back to Pokhara for the next stage of her recovery, her story captures what Foundation S's support makes possible: families reunited, children thriving, and care made accessible for every child with cancer in Nepal.

Simran's story
embodies
the statement,
"My Child Matters."

Thank you, Foundation S, for ensuring Simran matters.

Building Bridges for Pediatric Oncology in **Latin America**

Inside TeLeo's Collaborative Community of
Pediatric Hemato-Oncology Fellows

By Rocío Alonso

A regional training initiative led by Hospital Sant Joan de Déu is improving access to high-quality pediatric hematology–oncology education—and the experiences shared by fellows across Latin America highlight its practical, supportive, and genuinely reachable impact



TeLeo, an educational initiative of Hospital Sant Joan de Déu, is expanding access to high-level pediatric oncology training across Latin America through a free online platform in Spanish and Portuguese. Guided by leading regional and international experts, it promotes regionally adapted, context-based learning. Supported by Foundation S through its My Child Matters program, TeLeo offers multidisciplinary, high-quality content tailored to real clinical settings—particularly in countries where access to specialized training is limited, inequitable, or often unavailable in learners' native language.

Among its various courses and educational resources, **TeLeo offers the postgraduate program Fundamentals of Pediatric Hematology–Oncology**, aligned with the standardized curriculum established by the Latin American Society of Pediatric Oncology (SLAOP) for the essential competencies required in pediatric hematology-oncology fellow training units. This course delivers flexible, rigorous theoretical training for pediatricians completing their specialization in formally recognized pediatric oncology units in diverse environments across Latin America. The program features interactive classes while also providing recorded content accessible to other university-trained healthcare professionals seeking to strengthen their theoretical foundation.

Across its 2021–2022 and 2023–2024 editions, TeLeo has reached more than 400 fellows from up to 40 training centers in 12 countries. With the ongoing 2025 cohort, this reach continues to expand. The following three stories reflect TeLeo's impact on the next generation of pediatric hematologist-oncologists.

Dr. Viviana Tenazaca **(Ecuador - Guatemala)**

Viviana completed her pediatric oncology training at Guatemala's National Pediatric Oncology Unit (UNOP), complemented by clinical rotations at leading international centers such as Milan's Istituto Nazionale dei Tumori, Hospital Sant Joan de Déu, St. Jude, and Colorado Children's. During her training, TeLeo served as a useful academic companion, offering structured content that supported her learning at UNOP and exposing her to the ways in which both peers and Latin American experts adapt pediatric oncology practice to local realities, including the limitations commonly faced across the region. **"TeLeo has been a wonderful experience—a complete, interactive program that lets us learn from experts and connect with them,"** she says.

Now preparing to return to Ecuador, Viviana will join the pediatric oncology unit at Hospital del Niño Dr. Francisco de Icaza Bustamante, where her goals include strengthening early detection, supporting families holistically, and helping

establish a Flow Cytometry laboratory to expand diagnostic capacity. Viviana highlights TeLeo's accessibility and close mentorship, sharing insights from international rotations while learning from peers whose daily clinical realities mirror those she will encounter in her own practice when returning to her home country.

Dr. Rina Medina **(Honduras - Mexico)**

Rina began her specialization in pediatric oncology at the Hospital Civil de Guadalajara, adapting simultaneously to a new country, a new hospital, and the demands of hematology–oncology training. Initially cautious about yet another online platform after the pandemic, she soon realized TeLeo was different: live, dynamic, and deeply interactive.

Over three years, she claims TeLeo became **"one of the most valuable tools"** in her training—a space where she presented cases, asked questions, and learned alongside peers facing similar challenges. She says it remains a cornerstone of her professional growth.

Dr. Mariuska Forteza (Cuba)

Dr. Forteza leads the Pediatric Oncology Service and chairs the National Pediatric Oncology Group in Cuba. Her leadership and experience in neuro-oncology, lymphomas, and solid tumors have helped connect TeLeo to fellows and specialists across the island—from Havana to Holguín.

Despite connectivity hurdles and even power outages, Cuban participants consistently join live sessions or access its recordings.

For Dr. Forteza, the program represents **"a significant step forward in medical education"** for them offering a broad, global perspective and access to world-class expertise.

A Regional Vocation, **a Shared Commitment**

The path to becoming a pediatric oncologist in Latin America is often shaped by vocation, perseverance, and the willingness to cross borders—geographical, institutional, and personal—to access the training needed to care for children with cancer. TeLeo seeks to honor that commitment and the need for connection by expanding opportunities for specialized education, helping narrow the gaps. In a field where the best outcomes depend on staying connected, learning from different approaches, and sharing experiences with peers facing similar constraints, TeLeo fosters meaningful learning opportunities that even extend beyond the formal curriculum.



The Power of Healing with the Heart

By Jazmín Servín

Stories never begin where we think they do. They start long before, in the silences, in the small acts that seem like nothing... yet weave the invisible thread that leads us to our destiny.

Since I was a child, I dreamed of becoming a doctor. Not only to heal and offer relief, but because I wanted those who came to me to feel understood— a little braver, a little less alone. And for a long time, I truly believed I was doing that... until life, with its tenderness and its harshness, showed me that I still had to learn the most important thing: how to heal the soul.

My path changed the day I met Marcos. He was fifteen, with a smile that defied sadness. He had lost his mother to

cancer, and his father had never been present.

His brother Isaac, only slightly older, was his refuge—his improvised father, his silent hero.

Marcos lived in Caragatatay, far from the capital. At thirteen he was diagnosed with colon cancer. He fought hard, and for a while, the illness retreated. But at fifteen, it returned with fury. I received him at the hospital, and from then on, his story became tied to mine. He went through surgeries, chemotherapy, and endless days of struggle. But the cancer gave no respite. When he turned eighteen, we learned it was advancing with no possibility of cure.

I looked at him and felt that words were not enough.



As a hemato-oncologist, I had been through similar situations many times before, but this time was different. Marcos was almost a child, and he had no parents to hold him. His brother did everything he could, but he too was lost, trying to be strong while their world collapsed.

And there I was—his doctor—wanting to help, yet not knowing how. I had to talk to Marcos about his illness, about the possibility of dying, but when I tried, I froze. I discovered, to my horror, that I didn't know how to speak to him about something so human, so profound.

I had spoken many times with the parents of my patients about these things, but never with the true protagonists.

That realization broke me... and transformed me. I realized that I knew how to care for bodies, but not hearts. That I could prescribe medication, but not comfort. And I felt lost, powerless, frustrated... I sought help from a psychiatrist friend who, astonished, asked me:

—"You don't know about palliative care?"

No, I didn't.

And without knowing it, that question changed my life. I discovered a new world. A medicine that doesn't promise eternity, but does promise dignity. One that cannot always cure, but can always care.

A medicine that dares to face death without fear, and that finds in pain a doorway to the deepest love. I learned from wise people who opened their hearts to me. But I also discovered a great absence: Paraguay had no pediatric palliative care.

No child, no family, had access to that kind of support.

And I knew, with a certainty born from the depths of my being, that this had to change. That's how a dream was born.

With the support of my chief, Prof. Angélica Samudio, and the strength of **Fundación Renaci**, we joined hands with the **My Child Matters program of Fundación S**. Together we imagined the impossible: the first Pediatric Palliative Care Service in Paraguay.

In 2023, we formed a small but powerful team: two doctors, a nurse, a psychologist, and a mountain of hope.

We listened to families, to professionals, to children.

With the help of **Dr. Mercedes Bernadá from Uruguay**, a pioneer in Latin America, we shaped a model of care that was integral, humane, and full of love.

Then we created tools, databases, protocols, and a

Palliative Care protocol on the Telenec virtual platform—another project of Fundación Renaci and Fundación S—so we could support those who live far away, because love has no distance.

Today, in the third year of the project, we are already caring for our first children at the newly inaugurated **Center for the Well-being of Children with Cancer of Fundación Renaci**. And every day I spend there, I feel that life returned me to my purpose.

Every day I see how something born from pain becomes hope. Palliative care has not only changed the way I work: it has changed the way I live. Because I understood that medicine is not only science. It is also love, listening, respect, and the courage to face suffering without running away. It is saying "I'm here" when fear tightens the chest.

Today, when I see the children and families we accompany, I know that every tear, every word, every embrace holds immense value.

Marcos is no longer here, but his story lives on in every child receiving more human, more compassionate care.

He was my teacher, my silent guide.

None of this would be possible without Fundación Renaci, Fundación S, and all the hearts that believe no child should suffer alone. This alliance is not just a medical project: it is an act of faith in humanity. A silent revolution of love, empathy, and tenderness. It represents hope. It represents humanity. And, above all, it represents the certainty that when we care with the heart, life always has meaning—even in its final chapter.



Today I look back and understand that I did not choose this path: the path chose me. And if someday I'm asked what I learned, I will answer: that the most powerful medicine cannot be prescribed—it is given with the soul.

Tabletochki Believes in Personal Growth and Professional Development

The Story of Know - HOW

By Yuliya Nogovitsyna



Continuing medical education is crucial for healthcare professionals – especially in childhood cancer care, where every clinical decision matters. But in Ukraine, the Soviet legacy, the full-scale war, and severe public budget constraints have made it increasingly difficult for clinicians to access specialized training.

In 2023, Tabletochki Charity Foundation launched the Knowledge and Competency-Based Training Initiative for the Pediatric Hematology-Oncology Workforce (**Know-HOW**). The goal was to equip Ukrainian clinicians with the tools, skills, and confidence they need to deliver the best possible care to children with cancer and to integrate into the global professional community.

The Know-HOW Training Initiative is a My Child Matters-2023 award winner and is implemented with the financial and expert support of Foundation S, St. Jude Children's Research Hospital, and the American Lebanese Syrian Associated Charities (ALSAC). Thanks to the commitment of these partners and donors, Ukrainian healthcare professionals now have access to a level of professional development that would otherwise be out of reach. Their support has made it possible to transform good intentions into real, measurable progress for pediatric oncology in Ukraine.

Know-HOW is a comprehensive program for early- and mid-career pediatric hematology-oncology (PHO) clinicians, aimed at strengthening professional competencies and integrating Ukrainian specialists into the global childhood cancer landscape. The program promotes the following values: evidence-based decision-making, multidisciplinary teamwork, collaboration, ethical attitudes toward patients and their families, and lifelong learning.

Each year, ten participants are selected to join the program. Their two-year journey includes international observerships, participation in international conferences, English language training, a Pediatric Oncology Master Course from the Princess Máxima Center, and practical training in research methods, biostatistics, and communication skills.

To date, 30 healthcare professionals have joined Know-HOW – a significant share of Ukraine's pediatric oncology community. The group includes not only pediatric oncologists and hematologists but also surgeons, radiologists, transfusion specialists, intensivists, cytomorphologists, and ophthalmologists. This multidisciplinary approach ensures that the program's impact extends beyond oncology, strengthening pediatric healthcare as a whole.

Evaluating the impact of training initiatives – especially in Ukraine, where there are no hospital-based childhood cancer registries – remains a challenge. Yet the Know-

HOW team has developed creative ways to measure outcomes: participants' feedback, academic performance, and self-reported innovations help assess how much they are learning and applying in practice.

By late 2025:

- 27 international conferences have been attended by trainees.
- 16 participants completed observerships, introducing multiple clinical innovations in their hospitals.
- Two-thirds completed research and communication training.
- 40% improved their English proficiency from B1/B2 to C1.

Participants routinely describe their training experience as highly relevant and engaging.

Know-HOW is changing more than clinical skills – it is changing mindsets. From competition to collaboration, trainees are increasingly open to sharing knowledge and supporting each other's work. Instead of operating in silos, they co-organize local webinars, invite peers to speak, and seek joint solutions for complex cases. From dependence to initiative, graduates are now launching their own projects – some funded by Tabletochki, others independently. Among recent initiatives are:

- a burnout prevention program for PHO nurses in Kyiv and Lviv;
- routine CPR training for hospital staff in Lviv;
- blood donation promotion in a Kyiv hospital.

These projects may seem small in scale, but together they represent a profound shift – Ukrainian healthcare professionals taking ownership of change, even under the most difficult circumstances.

One of the most memorable moments of the year was the in-person gathering of all three cohorts in Kyiv. Despite ongoing security challenges, 29 participants came together to share experiences, celebrate progress, and inspire one another. The atmosphere was filled with motivation and a genuine sense of community. Out of this meeting grew new collaborations: second-opinion consultations, guest lectures, and mutual support across institutions that had previously worked in isolation.

This autumn, the first cohort of Know-HOW graduates completed their journey – a remarkable milestone proving that professional education programs implemented by motivated teams and supported by committed partners and donors can not only survive but thrive in wartime. Should the situation permit, Tabletochki will continue running this program to raise a new generation of competent, proactive, collaborative, and open-minded PHO professionals.



Nurse-Led

Innovation in Pediatric Oncology

The Transformative Role of Foundation S

My Child Matters Grants



By Rehana Punjwani

Nurses are not just caregivers—they are innovators, leaders, and advocates shaping the future of pediatric oncology care worldwide. MCM grants give them the recognition, resources, and autonomy to make this vision a reality.

Childhood cancer remains a major public health challenge worldwide, particularly in low- and middle-income countries (LMICs), where healthcare systems often face persistent constraints such as limited resources, workforce shortages, and inequitable access to care. In these contexts, nurses occupy a unique and vital position. As the largest group of healthcare providers and the professionals most closely connected to patients and families, nurses are ideally placed to identify pressing health needs and design practical, culturally sensitive interventions. The **Foundation S My Child Matters (MCM) Nursing Awards** exemplify how empowering nurses through targeted funding, recognition, and autonomy can significantly enhance pediatric oncology care while driving broader systemic improvements.

Since its inception in 2015, the MCM Nursing Awards have recognized the critical role of nurses in the fight against childhood cancer. Over eight years, **45 grants** have been awarded to nurses from **26 countries**, supporting projects that directly impact patient care, family well-being, and professional development. Initially, the grants provided **€5,000 over two years**, but this was later increased to **€15,000 over three years**, reflecting both the growing recognition of nursing-led initiatives and the expanded scope and ambition of the projects supported. Each cycle selects approximately **ten awardees**, chosen through a rigorous application and evaluation process coordinated by the **International Society of Paediatric Oncology (SIOP)** and overseen by an international working group of expert nurses.



How to use a thermometer Lahore, Pakistan

The **focus of nurse-led projects** funded by MCM is both broad and deeply impactful. These initiatives range from **capacity building** and **infection control** to **cancer awareness, palliative care, psychosocial support, and early detection efforts**. Between 2015 and 2023, the distribution of projects demonstrates the priorities LMIC nurses from around the world have identified: 21 focused on building capacity, 8 addressed infection control, 5 advanced cancer awareness or advocacy, 5 improved palliative and pain care, while others targeted access to care, psychosocial support, early detection, and treatment

abandonment. These projects illustrate nurses' deep understanding of the complex needs of children with cancer and the families who care for them.

The **geographical distribution** of awardees further highlights the global reach and inclusivity of the program. Nurses from Pakistan (5), Tanzania (4), Ghana (3), India (3), Mexico (3), and several other countries, Cameroon, Indonesia, Palestine, Philippines, Uganda, and Vietnam, have been recognized. The awards also extend to regional projects in Africa and Asia, as well as initiatives in countries such as Botswana, Burkina Faso, Cambodia, China, Colombia, Democratic Republic of Congo, El Salvador, Iraq, Turkey, Ukraine, Zambia, and Zimbabwe. This diversity underscores the program's commitment to empowering nurses in regions where the burden of pediatric cancer is often greatest and resources are most limited.

Nurse-led projects are distinguished by their **patient- and family-centered focus**, in contrast to many physician-led initiatives, which are often broader, country-level, and primarily focused on cure. Physicians typically prioritize medical treatment and systemic interventions when applying for funding, whereas nurses design projects that address **day-to-day care, symptom management, family support, and quality of life**. Cancer, a catastrophic disease, affects not only the child but the entire family. Nurses continually at the bedside gain intimate insight into the families' needs. The MCM Nursing award projects reflect this understanding, emphasizing interventions that improve survival, reduce suffering, and enhance overall well-being — from psychosocial support to nutritional guidance, infection control, and treatment adherence strategies.



Training workshop neutropenic fever for families. Hospital General de Tijuana, Mexico

The **significance of nursing-led projects in LMICs** extends beyond patient outcomes. By allowing nurses

from LMIC to lead initiatives, **MCM fosters autonomy, empowerment, and professional visibility**. These nurses gain a “seat at the table,” contributing their frontline perspectives to decision-making processes that shape pediatric oncology care. These projects promote **innovation, evidence-based practice, and professional development**, while also strengthening the credibility of nursing as a discipline in global health. By supporting nurses in these leadership roles, MCM demonstrates that the knowledge, judgment, and creativity of bedside caregivers are essential for designing effective and culturally appropriate interventions.

The Sanofi Collective, Foundation S is unique as an independent NGO in its explicit recognition of nurses and the provision of MCM funding for projects that they deem most critical. Unlike broader institutional or medical priorities, nurses are empowered to select topics that address tangible challenges in patient care and family support. This approach ensures that initiatives are highly relevant, targeted, and often transformative, directly influencing local **patient survival and quality of life**. The autonomy afforded by MCM grants strengthens the LMIC nurses' confidence, leadership skills, and advocacy capacity, further contributing to sustainable improvements in pediatric oncology care.

Moreover, nurse-led initiatives often serve as catalysts for **systemic change**. By identifying gaps in care, piloting innovative interventions, and demonstrating measurable improvements, these projects can inform hospital policies, national guidelines, and broader healthcare practices in settings where the World Health Organization Global Initiative for Childhood Cancer is aiming for 60% survival for six index cancers by 2030. The dual focus on care and capacity-building helps ensure that knowledge and skills are retained locally, fostering resilience and sustainability in health systems where resources are constrained. In effect, nurses not only improve the immediate care environment but also shape the broader framework in which pediatric oncology services are delivered.

In conclusion, the Foundation S My Child Matters Nursing Awards highlight the **critical role of nurses in pediatric oncology**, particularly in LMICs where resources are limited and the burden of disease is high. By funding and recognizing nurse-led projects, MCM empowers frontline caregivers to identify needs, innovate solutions, and implement interventions that directly improve survival, quality of life, and family well-being. Beyond the bedside, these projects strengthen the nursing profession, foster leadership, and drive systemic improvements in healthcare delivery. Nurses, through their unique perspective and close connection to patients, are not just caregivers — they are innovators, advocates, and leaders whose projects directly improve survival, quality of life, and family well-being in pediatric oncology worldwide.

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No Child should be Left Behind

Home Away from Home (HAFH) Program

By Alejandra Mendez



In 2023, I was invited to join the MCM Expert Committee — I immediately accepted, drawn by the idea of joining forces between **Childhood Cancer International** (CCI, the organization I proudly serve) and **Foundation S**. Both organizations share the same goal: to improve access to care for children diagnosed with cancer and to enhance the quality of life of patients, survivors, and their families.

At CCI, we firmly believe that only through collaboration will we achieve a world where at least 60% of children survive cancer.

My first experience was, honestly, a bit intimidating. When I attended my first meeting, I realized I was the only member without a medical or scientific background. The room was full of brilliant professionals — doctors, nurses, researchers — all with impressive careers in oncology. I was there representing

the *people with lived experience of cancer* (PWLE), a role I hold with great pride as the mother of a childhood cancer survivor. Still, I couldn't help but wonder if I had been invited just to "tick a box."

I quickly realized how wrong I was.

The committee was genuinely interested in our perspectives. They listened attentively, asked thoughtful questions, and truly valued our contributions. I felt heard, respected, and considered in every single decision. I remain deeply grateful to Isabelle and the entire committee for giving real meaning to inclusion — for making sure our voices mattered.

In the second year, my admiration only grew. The committee showed great openness to new ideas and was eager to design programs that went beyond medical care alone. They embraced a holistic vision — one that included psychosocial dimensions and focused on strategies to reduce mortality rates and improve treatment adherence among children. This shared sense of purpose became the heart of our collective ambition.

Research and experience show that one of the main reasons parents don't seek treatment — or abandon it midway — is not a lack of medical services, but socio-economic hardship. Many treatment centers are located in large cities, making it too costly for families from remote areas to stay during their child's treatment. Accommodation provided enables children and families to overcome this obstacle, and to stay free of charge in a home where their psychosocial and essential needs are met.

This is how the **Home Away from Home** (HAFH) Program was born — strengthening the partnership between CCI and Foundation S. The program addresses both the medical and psychosocial needs of families, recognizing that they are equally essential to improving survival rates for children with cancer worldwide.

In 2024, we launched our first joint call for proposals. We received 30 remarkable applications from CCI member organizations — all passionate projects with the potential to transform survival outcomes for children in low- and middle-income countries.

Three were selected for funding to build *Home Away from Home* houses in Bolivia, Malaysia, and Zambia. The impact has been truly moving. We have seen how providing families with a safe place to stay near treatment centers not only reduces treatment abandonment but also brings hope and dignity during the hardest moments.

I had the honor of attending the inauguration of the house in La Paz, Bolivia, where I met one of the mothers staying there. I cried as I listened to her story: without that house, she said, she would have had to return to her village

because she couldn't afford to stay in the city — even knowing that abandoning treatment would mean losing her child. That house quite literally saved her son's life.

In 2025, we received 27 more compelling and worthy proposals from CCI member organizations around the world. Thanks to continued support, we were able to fund the construction, renovation, or operational costs of six new homes in Peru, Mexico, Ukraine, Ethiopia, Kenya, and Nepal.

We have faith that this program will keep growing — touching more lives, saving more children, and supporting more families through their most difficult journeys.

Thank you, Foundation S and the MCM Program, for believing in CCI and for sharing our conviction that **no child should be left behind**.

Thank you for teaming up with us to ensure that every child with cancer has equal access to life-saving treatment and the best possible quality of life.

I can't wait to see how this program continues to grow — and how many more lives we will save together.

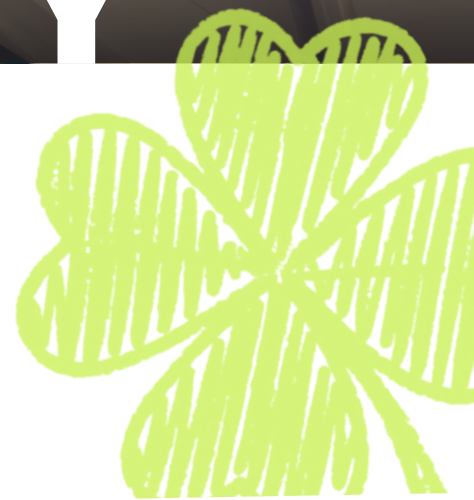




A MOTHER'S JOURNEY

Zenia's Story

By Hebah Mushtaque





It has been a long and testing journey since my daughter, Zenia, first fell ill. Her treatment began in 2023, marking the start of what became a 2.8-year struggle filled with fear, hope, and faith.

We live in Ranipur, and when Zenia first started having fever on and off, we took her to a nearby clinic for treatment. But despite several visits and medications, her fever would not go away. As a mother, I could sense something was wrong, and my heart was restless. Eventually, we took her to a bigger hospital, where initial tests were done. The doctors there told us that blood cancer was suspected, and they immediately referred us to Indus Hospital & Health Network (IHHN) in Karachi.

I still remember the day we arrived at the Pediatric Oncology Emergency Department (ER) of IHHN. I was scared and confused, but the doctors and nurses were kind. Zenia was admitted and started treatment under the care of Dr. Kishwer Nadeem. Those early days were the hardest — I had to travel alone with Zenia to Karachi, leaving my 1.5-year-old baby back home in Ranipur. My husband, a military personnel, was deployed in the rugged and mountainous terrains of Pakistan, so I had to manage everything on my own. It's been an emotionally and physically exhausting journey, but I know I have to stay

strong for my daughter.

As the treatment progressed, we faced many ups and downs. On 4th March 2024, Zenia had her first fit — her eyes were fixed, and my heart nearly stopped from fear. And again, on 12th April 2024, she had another episode and was hospitalized. The doctors did an EEG, which showed focal epileptic discharges. It was terrifying, but the team at IHHN managed it well, and Zenia continued with her chemotherapy. They were very kind to us and also provided a monthly allowance, which helped us manage her care.

For a while, things seemed to be improving. We were nearing the end of her maintenance cycle, and she was about to receive her last chemo session. I allowed myself to hope again. But then, we received the devastating news — the disease had returned, this time spreading to her brain. It felt like the world had collapsed around me.

Now, Zenia is on palliative care, supported by the wonderful team at IHHN and its Shared Care Centers. We have been told that in case of any emergency, we can go to the Shared Care Center in Larkana. I am currently pregnant again, and life has not been easy — every day comes with its own challenges — but I am grateful that Zenia is still with us and it feels better most of the time.

“Even though she is on Comfort Care and we would have been unable to afford all the treatment our daughter has received, we still have hope and pray for a miracle”



BEYOND HEALING



A Journey Through Experience

By Sol Irupé Aponte Bonzi

I still remember the shifts and rounds in the Hematology-oncology ward when I had just finished my medical degree and was taking my first steps in Pediatrics. Being with children was always my choice; their joy and resilience taught me to look at life with hope, defining my professional vocation from that very first contact.

As I was completing my years of residency in pediatrics, there was no doubt about what I wanted.

If illness and hospitalization represented the highest degree of vulnerability for the child, my place was to be there. Caring for that child, supporting their parents, and striving

to help them return home became my goals in life.

I started my subspecialty thanks to **Prof. Dr. Angélica Samudio**, who opened the doors to Pediatric Hemato-Oncology for me, providing me not only with her knowledge and experience but also giving me her unconditional support and complete trust to become a professional who respects her work, is willing to give more than necessary, and loves what she does every day of her life.

In the Pediatric Hemato-Oncology Department, I held different roles, such as outpatient physician, on-call doctor, and inpatient ward doctor. During this time, I discovered that my other great passion is being able to share my knowledge and that of my mentors with other students and doctors who are doing their rotations in our specialty. That's how I gradually dedicated myself to teaching until several years ago I managed to join the faculty of teaching authorities in the Pediatric Hemato-Oncology Specialist Training Program at the Hospital de Clínicas of the Faculty of Medical Sciences of the National University of Asunción.

Little by little, I became involved in different projects, discovering that quality care and the success of patient treatment are not based solely on assistance but on the continuous analysis of our weaknesses and strengths, always striving to improve and move forward. I started as a collaborator on the decentralization project and the creation of satellite clinics for the **ReNACI Foundation** for the **My Child Matters Program of the S Foundation**, bringing specialized medical care to rural communities in the interior of the country. This experience taught me the importance of bringing resources and knowledge to where they are most needed, thereby ensuring equity in access to health care.

Later, continuing with the S Foundation's partnership for the MCM program in Paraguay, I collaborated in the creation of the Catheter Clinic, designed to ensure safe vascular access for our patients, through the joint work of surgery and nursing for the implementation of fully implantable catheter management guidelines, thus reducing invasive and painful procedures for children.

Later, I had the opportunity to participate in a digital educational project: TELENEC, in which I am responsible for coordinating training courses aimed at pediatricians and family doctors on warning signs and suspected cases of childhood cancer. The use of digital platforms allows this training to reach different parts of the country, strengthening early detection and comprehensive care for patients.

Finally, after much effort and going through various stages, we have managed to initiate a pioneering project in our country. Considering what happens after cancer, what challenges the child or adolescent and their family

face upon being discharged, and whom they should turn to regarding the different physical, emotional, affective, and social aftereffects that arise as survivors of childhood cancer—these questions took me beyond what specialists are normally accustomed to. We fight so hard to overcome the disease and forget that there is an entire life “afterwards” to which we cannot turn our backs or let go of our hand. The creation of the Survivor Clinic is the result of the support and backing of the S Foundation to offer the first program for childhood cancer survivors in Paraguay. It is to be carried out at the ReNACI Foundation Wellness Center, where we aim to consolidate a comprehensive approach to pediatric oncology care, combining direct care and the training of multidisciplinary teams.

The Survivor Clinic provides support to children and adolescents beyond treatment, promoting their physical, emotional, and social well-being, strengthening the continuity of care, and focusing on the real needs of patients who have overcome childhood cancer. This program includes:

- Multidisciplinary work with specialists from different areas.
- Clinical guidelines for primary care physicians, aimed at the comprehensive follow-up of survivors.
- Promotion of healthy lifestyles and social reintegration, encouraging the active participation of survivors in their community.

Every patient I accompany reminds me that medicine is not just about healing bodies: it's about supporting lives, maintaining hope, and building human connections that go beyond hospitals.

From trips to rural areas, to the creation of specialized clinics and educational programs, to care for survivors, each stage has been a link in the same purpose: bringing science with tenderness, knowledge with humanity, and hope with action.

I am Sol Aponte, a Pediatric Hemato-Oncologist. Professional, mother, and wife. I balance my life in these three areas, and each one of them completely fulfills me. This specialty touched the most intimate parts of my humanity and repeatedly placed me in the shoes of others. Many times, it found me defenseless, but it brought out my greatest strength: not giving up, neither now nor later.

Obviously, the journey continues, the challenges are great, but the reward— seeing the children grow, regain their health, and reintegrate into their community— makes every effort worthwhile.

We continue TOGETHER in this fight, because we not only long to cure diseases but also hope that the marks we leave along the way help build lives.



Little Gloria Among's Journey

The Fight Against Retinoblastoma in Rural Uganda

By Moses Okipi

Gloria Among, a five-month-old infant from Omolokonyo Village in Kumi District, was only two weeks old when her mother noticed a white reflex in both of her eyes, more pronounced in the left. With no vision in the left eye and signs of rapid deterioration, the family sought care at Kumi Hospital, where trained eye health workers assessed her and referred her to Ruharo Mission Hospital in Mbarara.

Gloria's parents, who rely on small-scale farming of maize, cassava, and potatoes, had never travelled beyond their district. Nevertheless, compelled by urgency and hope, they undertook the challenging 580-kilometre, ten-hour journey to Ruharo Mission Hospital. With minimal resources, they borrowed money for transport after learning that the hospital provides transport reimbursement and meals during admission. The journey was especially daunting for the mother, who had limited travel experience and language familiarity, but her resolve remained unwavering.

Upon arrival on April 20, 2024, Gloria underwent a comprehensive evaluation, including imaging, an examination under anaesthesia, and laboratory investigations. Histology results received in July confirmed stage-one retinoblastoma, with no tumour spread into the retina, choroid, or sclera. The clinical team provided structured counselling and initiated a targeted treatment plan.

Gloria has since completed 11 cycles of chemotherapy combined with cryotherapy, intravitreal therapy, intravenous chemotherapy, and laser treatment. Her left eye, which had completely lost vision, was enucleated.

The postoperative socket remains clean, the implant is well-centred, and the prosthesis fits satisfactorily. Clinical progress in the right eye has been encouraging, with no tumour activity noted since June 2025. The vitreous

seeds initially seen have fully resolved. During her recent visit in October, her visual acuity was measured at 1/60, reflecting functional vision that enables her to navigate her environment effectively.

Like many children undergoing intensive cancer treatment, Gloria experienced periods of reduced immunity, exposing her to cough and malaria. With support, she received timely treatment. Children in her category are also vulnerable to neutropenia. Through rapid clinical response and donor-supported access to Neutromax, a drug critical for boosting neutrophil formation, these episodes have been managed proactively. Gloria's next comprehensive review is scheduled for February 2026.

Beyond her clinical progress, the family's resilience has grown notably. Initially dependent on travelling together, the mother now makes the long journey independently with Gloria, while the father remains at home to support the household.



Ruharo Mission Hospital has cultivated a distinguished niche in the delivery of specialised eye health services in Uganda. The hospital now serves as the national referral centre for the treatment of retinoblastoma, receiving patients from across the country and beyond.

Retinoblastoma treatment at Ruharo began 18 years ago, initially focusing on enucleation as the primary intervention. In 2009, systemic intravenous chemotherapy was introduced through the support of generous donors, expanding the treatment capacity significantly. Today, the hospital follows a neo-adjuvant chemotherapy protocol built on a combination of Carboplatin, Etoposide, and Vincristine.

The hospital's approach to retinoblastoma management is comprehensive and includes the following pillars:

- Awareness and health education
- Training of health workers in early identification, detection, and referral

- Investigations and confirmatory diagnostics
- Surgery and debulking procedures
- Therapy, rehabilitation, and long-term follow-up

Frontline health workers are continuously encouraged and empowered to refer suspected cases early. With specific support from Foundation S, the hospital undertakes awareness and health education, training of health workers in early identification, detection and referral. We have also been able to procure and install portable fundus camera to capture retinal images, and also procured indirect ophthalmoscope for funduscopy. Also key to note is transport and meals for children and their caregivers who travel long distances from remote communities, ensuring adherence to life-saving treatment plans.

Ruharo Mission Hospital maintains strong collaborations with the Uganda Cancer Institute, Mbarara Regional Referral Hospital, and partner hospitals across Uganda and neighbouring countries, including the Democratic Republic of Congo, South Sudan, Kenya, and Rwanda.

The programme's impact continues to grow. Annually, the hospital identifies, diagnoses, and manages an average of 140 new children with retinoblastoma, with over 150 cases projected this year. More than 8,749 suspected cases have been screened in the past six years. Since 2006, a cumulative total of 1,260 confirmed retinoblastoma cases have been managed. Over 500 intravenous chemotherapy sessions are administered each year. In the past five years alone, more than 400 health workers have been trained in retinoblastoma identification and referral, and over 21,224 IEC materials have been printed and distributed to strengthen community awareness.

Through the project titled ***Strengthening Retinoblastoma Care in Uganda: Advancing Early Diagnosis, Treatment Management, and Adherence for Children***, generously supported by **Foundation S under the My Child Matters program**, Ruharo Mission Hospital continues to advance national paediatric oncology outcomes.

This strategic support is anchored in three core priorities:

- Promoting early diagnosis through heightened awareness and extensive training of frontline health workers
- Strengthening treatment management by optimising care pathways and fostering multidisciplinary collaboration
- Enhancing treatment adherence by reducing financial and logistical barriers for families

The hospital remains deeply grateful to Foundation S and the My Child Matters initiative for their trust, partnership, and commitment to transforming paediatric cancer care in Uganda.

Promoting **Cancer Awareness** Among Young People in **Latin America**

#ChequeoAYA

By Mariana Nana

In Latin America, cancer among adolescents and young adults (AYAs) remains largely invisible. Each year, more than 120,000 people between 15 and 39 are diagnosed with cancer, and over 34,000 die. Yet most health systems in the region still do not recognize AYA oncology as a distinct area of care.

As a pediatric oncologist in Buenos Aires, I have seen too many young patients arrive with advanced disease — not because they neglected their health, but because symptoms were not recognized early and access barriers persist. Limited specialized centers, fragmented systems, economic hardship, and low health literacy all delay diagnosis. Many young people fear what a diagnosis might mean or minimize their symptoms, hoping they will go away. The result is late detection — and preventable suffering.

This reality inspired the creation of **#ChequeoAYA / #CheckUpAYA**, a regional initiative that combines research, digital communication, and artificial intelligence to promote cancer awareness and early detection among adolescents and young adults in Latin America. Our purpose is simple: **to make cancer visible for this population and empower young people to take charge of their health.**

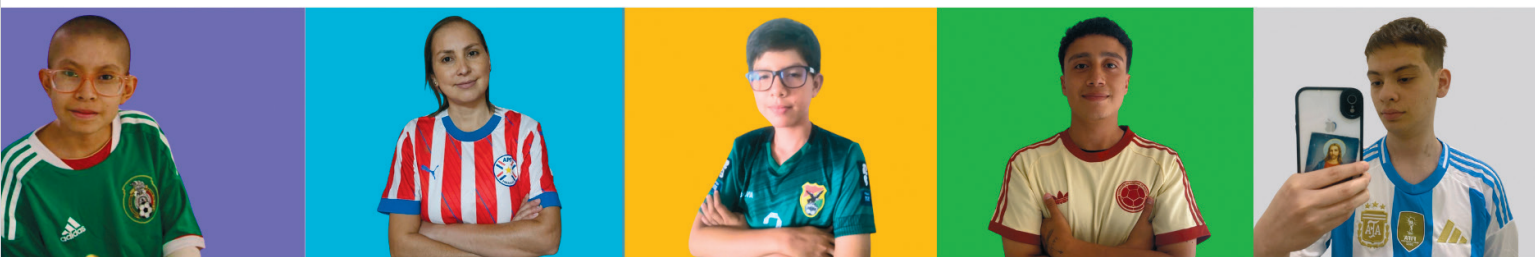
The project's main objectives are twofold: to develop engaging audiovisual materials that raise awareness about cancer warning signs and prevention, and to design an AI-powered chatbot that provides reliable, age-appropriate information and guidance about symptoms and access to care. Both strategies aim to build knowledge and confidence among young people, using the platforms they already use every day.

The initiative was born within the AYA Chapter of the **Latin American Society of Pediatric Oncology (SLAOP)**, which I currently co-chair, with the support of the **Pan American Health Organization - Cure All** and foundations such as **Fundación Natali Flexer**. It is led by a multidisciplinary team of physicians, psychologists, communicators, and developers from more than ten Latin American countries, united by the conviction that awareness saves lives...

We began with a regional survey to explore young people's knowledge, perceptions, and behaviors related to cancer and health-seeking. The anonymous, ethically approved survey — available in Spanish and Portuguese — was distributed through SLAOP networks, youth foundations, and social media. Hundreds of responses from nearly every Latin American country now offer a unique picture of what young people know (and don't know) about cancer.



#ChequeoAYA: Promoting Cancer Awareness Among Young People in Latin America



My child matters



SLAOP
Sociedad Latinoamericana de Oncología Pediátrica

FNDF
Fundación Natali Dafne Flexer
Ayudamos a niños y jóvenes con cáncer



These insights guide the next phase: the creation of five bilingual short videos in Spanish and Portuguese that address early symptoms, testicular and cervical cancer prevention, self-examination, and the importance of timely medical consultation. Developed with experts in communication and youth psychology, the videos should ensure messages that are scientifically sound, emotionally resonant, and culturally relevant.

In parallel, we are developing **CHAT AYA**, an interactive chatbot powered by artificial intelligence. This digital tool will provide personalized, validated information about symptoms, risk factors, and local healthcare resources in accessible and empathetic language. The chatbot is designed as a safe digital companion — one that can answer questions privately and guide users to seek medical help when needed.

Both the audiovisual content and chatbot prototypes undergo **review and feedback from key stakeholders**, including young cancer survivors, healthcare professionals, and communication specialists. Their participation ensures that all messages are credible, inclusive, and adapted to the realities of diverse local contexts.

Beyond raising awareness, #ChequeoAYA seeks to build a

regional culture of open dialogue about cancer. We want to move from silence and fear to knowledge and action. By normalizing conversations about cancer, we aim to reduce stigma, promote early consultation, and help young people feel more confident navigating the healthcare system.

One of the most rewarding aspects has been the enthusiasm of young people eager to participate, share, and learn. This confirms that when communication speaks their language, it becomes a powerful tool for empowerment.

For me, #ChequeoAYA / #CheckUpAYA bridges science, empathy, and technology. It grows from clinical experience but looks beyond the hospital — toward prevention, community engagement, and digital inclusion.

This project has been made possible thanks to a **Sanofi “My Child Matters” grant**, which supports innovative initiatives improving childhood and AYA cancer outcomes worldwide.

Our vision is simple yet ambitious: that no young person in Latin America should face cancer too late simply because they didn’t recognize the symptoms or didn’t know where to go. If even one life is saved because someone decided to get a check-up after seeing our campaign, the effort will have been worth it.

Desiderata and My Child Matters

Together on the Journey
Toward Cure

By Carolina Motta



For over 20 years, at Instituto Desiderata, we have been strengthening public policies that promote the health of children and adolescents in Brazil. Since beginning our journey in 2003, we have contributed to transforming the reality of childhood and adolescent cancer, the leading cause of disease-related death among young people aged 1 to 19 in the country. Over the years, thanks to the consistent work we established in Rio de Janeiro, we recently gained a critical boost through our strategic partnership with My Child Matters.

Since 2005, we have implemented Unidos pela Cura (United for Cure – UPC), a system-strengthening strategy focused on promoting and improving the early diagnosis of childhood and adolescent cancer. The initiative started in Rio de Janeiro, in partnership with SUS (Sistema Único de Saúde), Brazil's universal and free public healthcare system. Our main objective is to reduce the time between suspicion of cancer and the start of high-quality treatment for children and adolescents.

SUS, with its broad and interconnected network that spans from Basic Health Units (the primary entry point into the public healthcare system) to high-complexity hospitals, is the backbone of healthcare in Brazil. Strengthening early detection within this network is essential to ensuring equitable access and increasing survival chances for children with cancer.

Our Unidos Pela Cura (United for Cure – UPC) Strategy

Unidos pela Cura is built on three essential pillars:

Optimized Referral Flows: We work with public health managers and services to establish referral flows that ensure that a child with suspected cancer identified in primary care reaches a specialized pediatric oncology center as quickly as possible. In Rio de Janeiro, this work helped reduce the average referral time to 72 hours.

Professional Training and Capacity Building: We invest in ongoing capacity-building efforts for frontline providers in Primary Health Care and Emergency Care Units (Unidades de Pronto Atendimento – UPAs), preparing them to identify early warning signs and symptoms of childhood cancer.

Active Monitoring and Data-Driven Improvement: We use information systems to monitor results and identify opportunities for improvement across the network.

Over two decades, Unidos pela Cura has become a widely recognized and successful model in Rio de Janeiro,

strengthening the SUS through an integrated network of childhood cancer care.

Our Expansion to Pernambuco

In 2023, with our approach already consolidated in Rio de Janeiro, we moved toward expansion. Thanks to the strategic support of My Child Matters, we began implementing Unidos pela Cura in a new priority region: the state of Pernambuco, in Brazil's Northeast.

The technical and financial support from My Child Matters was instrumental in adapting our methodology to a particularly promising setting for scale. Pernambuco has high Primary Health Care coverage (73%), a significant number of new childhood cancer cases each year (approximately 410), and already has a State Policy for Pediatric Oncology Care and three accredited specialized pediatric oncology centers. Together, these factors created fertile ground for strengthening the referral flow, broadening impact, and accelerating improvements in access to diagnosis and treatment.

With the strength of this partnership, we launched extensive cross-sector coordination involving the Pan American Health Organization (PAHO), St. Jude Children's Research Hospital, State and Municipal Governments, the Ministry of Health, specialized hospitals, support centers, and numerous local partners. Guided by a strategic committee composed of representatives from 14 organizations, we achieved an important milestone for the state: **the establishment of a referral flow of up to 48 hours for children and adolescents with suspected childhood cancer** (something Pernambuco did not previously have) **along with enhanced training for frontline health professionals.** This achievement represents a structural advancement for pediatric oncology in the state and is the direct result of collective work involving health professionals, managers, and technical partners.

Our alliance with My Child Matters reflects a deep alignment of purpose and the belief that collaboration across organizations is essential to reducing health inequities. By supporting Unidos pela Cura, My Child Matters made it possible for us to bring a proven early-diagnosis strategy to a region where the impact on children's lives is especially significant.

Today, Unidos pela Cura in Pernambuco shows how a methodology developed in Brazil can inspire public policy and generate real impact when it's supported by partners who share the vision that every child, everywhere, deserves a fair chance at a cure. This is what unites us with My Child Matters and keeps us firmly committed to expanding the reach of this strategy.



When a
Collective Dream
Changes the History of
Childhood Cancer
in Paraguay

By Angélica Samudio

From my earliest days as a physician, one truth marked me profoundly: the deep inequality faced by children with cancer in low-resource settings. Day after day, I cared for young patients whose faces reflected both hope and fear. Their families offered everything they had, confronting not only the disease but also the limitations of a healthcare system that could not always respond.

In Paraguay, as in many Latin American countries, a childhood cancer diagnosis was not only a medical challenge — it was also a social and emotional one. Limited resources, lack of equity, and geographical barriers meant that too many lives were lost too soon.

That reality was heartbreaking, but it also ignited a conviction: this could and must change. I understood that real transformation would require collective effort, international cooperation, and a shared belief in what is possible when compassion meets knowledge.

Discovering an Opportunity

That belief took shape when I discovered *My Child Matters*, a Sanofi Foundation initiative created to strengthen childhood cancer care systems in vulnerable regions around the world. I was inspired to learn how this program was already transforming the lives of thousands of children across Latin America — building networks, training professionals, and opening doors where there had once been isolation and despair.

Three years later, the call for participation reached Paraguay. I remember the excitement — it felt like a light had been turned on after a long darkness. Together with a passionate and committed team, we submitted a proposal to create a *National Network for Childhood Cancer Care*, a project designed to integrate efforts, optimize resources, and ensure that no child would be left behind because of where they lived or what they had.

When our project was selected, I knew a new chapter was beginning for the children of Paraguay.

Building a National Network

Our project was declared of national interest — a milestone that gave us strength and legitimacy. We began by training healthcare teams, improving care processes, implementing quality standards, and establishing Centers of Excellence. New service areas soon followed:

- **Pain-Free Hospital**, focused on alleviating physical

suffering.

- **Catheter Clinic**, ensuring safe and compassionate procedures.
- **Psychosocial Support Programs**, offering essential emotional care for children and families.

As we advanced, it became clear that childhood cancer care must treat not only the disease but the whole human being. That understanding led us to introduce two groundbreaking areas in Paraguay: **pediatric palliative care** and **survivorship follow-up programs**, both crucial for providing dignity, continuity, and hope beyond active treatment.

TELENEC: Innovation to Bridge Distances

Paraguay's geography presented a unique challenge — long distances and limited resources left many families isolated from specialized care. We saw in technology a chance to bridge those gaps.

From that vision, **TELENEC** was born: a national tele mentoring network that connects pediatricians and family doctors from across the country to discuss complex oncology cases, share expertise, and coordinate treatment strategies in real time.

Thanks to this project, digital innovation became a tool for equity. In only 18 months, TELENEC grew from 4 satellite clinics to **50 active virtual sites**, connecting more than **300 professionals** and benefiting over **500 children and families**.

Where before we could reach families only through long and difficult journeys, we now connect instantly — guiding diagnoses, supporting doctors, and saving lives. Distance is no longer a barrier; collaboration has become our bridge.

More Than Numbers: Building a Movement

With time, we understood that the most meaningful achievements cannot be captured solely in data. The true strength of *My Child Matters* lies in its capacity to transform mindsets and create a sense of shared mission.

In Paraguay, this purpose became a **movement** — one that fights inequity, promotes continuous education, and places children at the heart of care.

It is a movement built on cooperation:

- among healthcare professionals who share a vision of excellence,

- among institutions that believe in long-term impact,
 - and among families who trust that change is possible.
- And it is a movement that continues to inspire hospitals and organizations across the country to adopt best practices and expand the reach of compassionate, high-quality care.

Gratitude: 16 Years of Cooperation and Shared Hope

None of this would have been possible without the vision and sustained support of the **My Child Matters** program and the **S Foundation**, whose 16-year commitment to improving childhood cancer care has changed lives across the globe.

I am deeply grateful for their partnership, guidance, and trust. My heartfelt thanks also go to the **My Child Matters Expert Committee**, whose technical leadership and collaborative spirit have built an international community where science, innovation, and compassion converge.

In Paraguay, we owe special recognition to **Fundación Renaci**, our steadfast partner. Their dedication has strengthened and expanded our work. Together the Expert Committee, the **S Foundation**, and **Fundación Renaci** have shown that long-term collaboration can transform realities and cultivate enduring hope.

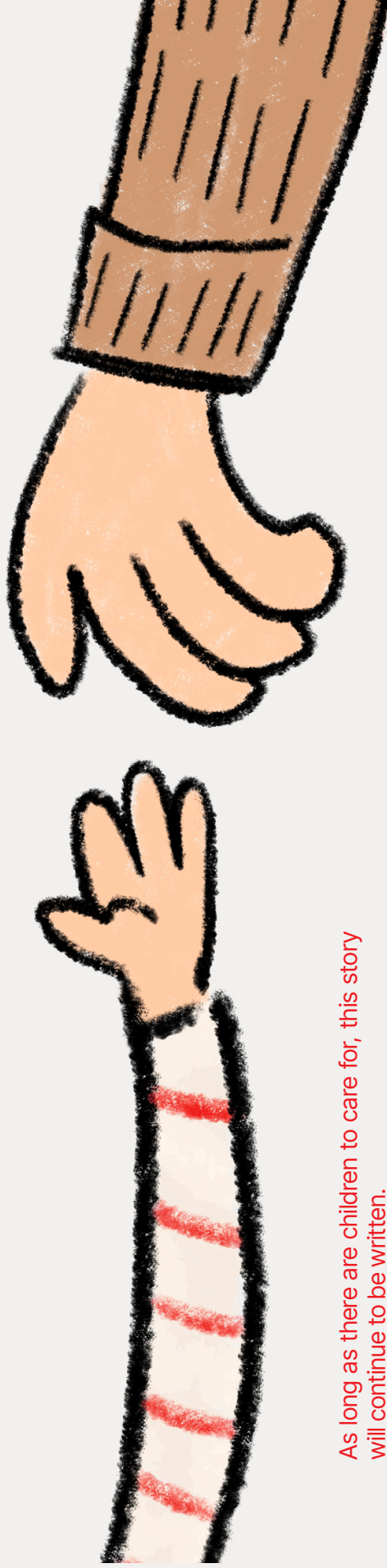
A Story Still Being Written

Sometimes, when I walk through the hospital and see a child smiling after chemotherapy, I remember why we began. I think of the early days, when it seemed impossible to change history and I realize that every effort, every alliance, every sleepless night has been worth it.

My Child Matters was not just a program; it was a seed. A seed planted in adversity that today blooms into a model of hope, innovation, and life.

Because when cooperation becomes action, and love for children guides every decision, it is possible to change destinies.

This story is not mine alone. It belongs to all who believed that childhood cancer in Paraguay could have a different ending. It belongs to a team that learned true strength lies in working together. And most of all, it belongs to every child who, thanks to this collective effort, now has a new opportunity to dream.



As long as there are children to care for, this story will continue to be written.

SJH and the Power of CleverCharts

By Trish Scanlan

SJH is a young 9 year old boy from the island of Pemba off the coast of Tanzania – part of the Zanzibar archipelago. Over the course of 18 months he started feeling worse and worse. He developed swelling in his neck. Then some tummy pain, followed by abdominal swelling. Then he woke at night sweating so much he had to change his bed clothes. He had never been sick in all his life prior to this time and his parents were extremely worried. They initially took him to local traditional healers repeatedly but after a year of treatment his symptoms were worse. He now had new swellings under his arms and in his groin.

When mum took him to the local hospital on Pemba Island they noted he was anaemic and gave him a blood transfusion. He was also losing weight so with all these symptoms they gave him anti-TB treatment for 3 months. But it did nothing to help him. Finally, they referred him to the larger Island of Unguja (known as 'Zanzibar').

There he was seen by one of the local Paediatric Oncologists who trained on the Masters/Fellowship course developed by Tumaini la Maisha in partnership with Muhimbili University of Allied and Health Sciences. She quite rightly suspected Hodgkin Lymphoma and took a biopsy which confirmed her suspicions. In fact he had the most advanced form of the disease – stage 4B – involving his lungs and spine. He was registered in the **CleverCharts Electronic Medical Record System (EMRS)** for children's cancer and his case was discussed every 2 weeks at the national meeting.

After 4 cycles of first line treatment it was time to assess his response to treatment. It was agreed that this was unfortunately inadequate and he was referred to the mainland and Muhimbili National Hospital to begin a further 4 cycles of second-line chemotherapy treatment. Each dose and response was recorded carefully in his EMRS file. The local team in Zanzibar were kept up to date of his progress every 2 weeks. Once the chemo was completed



he was assessed and everyone was delighted to find he was in remission. Per protocol however he still needed to be referred onwards again – this time across the city to the Ocean Road Cancer Institute where he received radiotherapy for a month to his abdomen and chest.

He was discharged in full remission on the 18th of October and is due back for review on November 28th 2025.

How do I know all this? Because it is all carefully recorded in our CleverCharts EMRS for paediatric oncology!

As you can see – his treatment is a wonderful example of multi-modal complex care delivered across multiple hospitals collaborating together all carefully documented thanks to the CleverCharts Programme. This EMRS allows safe and comprehensive referral between distant hospitals. Existing and subsequent treatments and assessments are all carefully recorded and accessible to the new and previous doctors keeping the child on the right track at all times and sites; and making sure that each child has the very best chance of cure.

Today SJH is back and school and thriving and our colleagues in Zanzibar are looking forward to seeing him and will continue to use CleverCharts to update his progress for all to follow.



FUNDACION NUESTRA ESPERANZA-OUR STORY

By Maria Cecilia Quiroga

Back in 2012, a group of friends decided to help families at the oncological ward of the Children's Hospital in La Paz, Bolivia, providing some medicine, blankets and clothing. During five years, they visited the ward regularly. During these visits they realized that parents had no place to sleep, they would gather cardboards and put them on the floor inside the hospital, or they found shelter inside cash

machines on the street. They also noticed parents would only have a piece of bread and a cup of tea as their only meal of the day, sometimes leftovers from their children's hospital meals.

This group of friends somehow heard about shelters in other countries that offered a place to sleep and a warm

meal to parents of children with cancer that had to leave their homes to get treatment. EUREKA!!!! In 2017, The idea to do something similar blew their minds. In a bit more than a week, they had rented a small, empty apartment close to the hospital, contacted friends willing to help and they were able to fully furnish the place and start sheltering a few parents. The place was small, but had a big heart and big dreams. After two years, thanks to donations and fundraisers, they were able to move into a bigger three bedroom, two story rented apartment and founded what today is Fundación Nuestra Esperanza. They started to give shelter to oncological families from the Children's Hospital and Hospital Materno Infantil, both of them for low income families. The apartment, called "Casita Utaja", was located close to both hospitals.

After three and a half years growing as a family, offering psychological support, free meals and shelter, Fundación Nuestra Esperanza, already a CCI Member (since the time it was ICCPO) had the opportunity to apply to the Home Away From Home Project, funded by CCI and Foundation S My Child Matters. The application process itself was already a gift. It gave Fundación Nuestra Esperanza the opportunity to self-assess, look ahead, plan accordingly, think about sustainability, and analyse the impact of our work so far. It gave us the opportunity to work with brilliant young professionals who allowed us to learn through their knowledge and input. We put many, many hours of work, and dreams, and drafts, and numbers and more drafts, until January 3, 2024 when praying and crossing fingers, we submitted the Home Away from Home Application Form. We just had to wait, and hope.

On February 15th, 2024, International Childhood Cancer Day, news was released by CCI and Foundation S.

Fundacion Nuestra Esperanza Bolivia, had been awarded with a grant, along with Zambia and Malaysia. News was received with tears of joy, thinking "Really? We got it? WE GOT IT!"

Thank you God, we got it!

Now it was time to look for a house. A lesson on patience, tolerance, time, negotiations... Miraflores, the neighbourhood where hospitals are located, is one of the most expensive in the city, given that many hospitals and medical schools and diagnostic centres are around. At the same time, Miraflores is one of the oldest, most traditional neighbourhoods in La Paz. Constructions are old and anything we decided to buy, would need major renovations. After looking for countless houses, we found our home. A cozy house with big possibilities to reform and adapt to our needs.

Now it was time to convince the board this was the place, present them the price, renovation costs, time frame. It was not easy, but we were so passionate that we managed to

get approval and bought the house in July. It was time to get the work done!

Architect, floor plans, budget...the fun part had begun!

In the meantime, we had to get a loan to be able to finish remodeling, and carry on different fundraisers, and visit possible donors to furnish our new home, acquire kitchen appliances and everything else needed to have an adequate place for our patients and their families. We finally moved into our new Home Away From Home on November 7th, 2024, increasing our capacity **by 200%**!

This was one year ago and we thought all the work was done, but...

Having a bigger home, required more responsibilities, more work and learning even more.

January 2025 we had our CCI evaluation visit with Alejandra Mendez and Ellen Salvado. They loved our Home Away From Home, were able to share with volunteers, parents and children. The most important part of the visit for us was getting feedback and advice, all done with love and care. One of the topics they really recommended was data collection and, not least important, safe transportation for our families.

We are so proud to share the news that Susana Arze, one of our volunteers, came up with a wonderful Administrative and Data Recording System, and now, all our information, services, patient records, inventories, and more, are digitally managed and updated on a daily basis.

We also have a Safe Transportation service, which is financed by Mediterranean Shipping Company and takes our families to and from different destinations, such as Hospitals, Radiotherapy centres, bus stations, or other places of need.

We created a complete and sustainable AOP, and are in the process of improving inside communication with our volunteers and information within the community.

We continue with our regular fundraising activities and come up with new ones. Every day there is something new to learn. We receive the support of so many people and companies, that we can only feel blessed.

As I have said it on several occasions, we are forever grateful with **CCI and Foundation S My Child Matters**, especially on behalf of our children and their families, but also as volunteers, because now we can improve survival rates by offering a bigger home, having less treatment abandonment and actually feel that we can, indeed, save lives.

Thank you!

VIGICANCER

The Seed to Develop a Colombian Transdisciplinary Network for Childhood Cancer



By Oscar Ramirez, Vivian Piedrahita, Monica L. Quijano-Lievano, Andres Portilla, Karina Grillo, Maria X. Castro, Jesus Ardila, Rebeca Rivera, Luis E. Bravo, and Paula Aristizabal

*It's a piece that could easily belong in an academic journal, but we're proud to publish it in **CancerWorld** Magazine.*

Colombia, with more than 52 million inhabitants, is the third most populous country in Latin America. Childhood cancer is the second leading cause of death among Colombian children aged 2–19 years, making it an important public health concern. Colombia's Childhood Cancer Clinical Outcomes Surveillance System, VIGICANCER, was established in 2009 in Cali, the third-largest city in the country, in an alliance with Cali's Population-Based Cancer Registry and the POHEMA foundation and with the vital support of the Foundation S (formerly Sanofi-Esper foundation, France). VIGICANCER registers children and adolescents (< 19 years) newly diagnosed with cancer receiving treatment at 27 participating Colombian institutions. VIGICANCER collects demographic and clinical data and conducts quarterly active surveillance to document outcomes, such as death, disease relapse, occurrence of second malignancies, treatment abandonment, and loss to follow-up. VIGICANCER analyzes and disseminates valid, reliable, and timely population-based data on clinical outcomes from over 12 000 Colombian children with cancer registered to date.

VIGICANCER's results are discussed regularly with Colombian health authorities and disseminated to the scientific and public health communities through publications and presentations at national and international meetings. Among the important findings from VIGICANCER were the lower survival of Colombian children with brain tumors compared with comparable cohorts in other regions, and the increased early mortality of children with solid tumors during the COVID-19 pandemic, attributed to more advanced stage at presentation and reduced treatment effectiveness due to disruptions in care.

VIGICANCER provides important, real-world, comprehensive, actionable population-based information, guides multilevel interventions, and informs local and national public policy. At the same time, it provides timely feedback to clinicians and administrators at participating institutions. Moreover, VIGICANCER has proven to be a springboard for collaborative network-building. In 2018, a strategic alliance was formed between VIGICANCER and the Asociación Colombiana de Hematología y Oncología Pediátrica, ACHOP [Colombian Association of Pediatric Hematology and Oncology]. With the continued support of Foundation-S and new support from ACHOP, VIGICANCER successfully integrated to its network the two largest cities in the country, reaching about 45% coverage of the childhood population nationwide. Currently VIGICANCER

spans 10 cities and includes about 60% of the childhood population nationwide. VIGICANCER also amplified its impact by establishing the first transdisciplinary Colombian collaborative network at both national and international levels.

The strong networks shaped by VIGICANCER have spread to other regions in Latin America. For example, another key milestone is the fruitful South-South alliance with the United States–Mexico Binational Health Commission, in Tijuana, Mexico. In this partnership with support from Foundation-S, the Colombian-Mexican team established the first population-based cancer registry in north-western Mexico (BajaREG) and the Pediatric and Adolescent Cancer Registry Surveillance System (PACARSS), modeled after VIGICANCER. The successful operation of these two initiatives was achieved through mentoring by the VIGICANCER team on developing needs assessment evaluations, adapting local protocols, and training the Mexican staff in data collection and analysis.

VIGICANCER has made significant contributions locally and regionally by producing valid and reliable population-based data, serving as a foundation for public health prioritization, providing a replicable model for other low- and middle-income countries in Latin America, and advancing scientific and academic progress in the region.

In 2024 VIGICANCER, in partnership with ACHOP, convened stakeholders from governmental, grassroots, academic, and patient support organizations to build consensus on the implementation of strategic initiatives targeting key milestones to improve childhood cancer survival in Colombia. The key focus areas included early detection of childhood cancer, standardization of cancer-directed and supportive care management, centralization of provision of complex cancer care and optimization of referral pathways, and growth of collaborative clinical research. A transdisciplinary leadership team is responsible for directing the development of comprehensive and consensus-based methodological approaches for each initiative. Therefore, committed to reducing morbidity and mortality in Colombian children with cancer, this partnership between ACHOP and VIGICANCER developed a strategic roadmap and integrated a broader transdisciplinary network, including clinicians from critical subspecialties involved in the care of children with cancer. This approach was informed by VIGICANCER results, which highlighted that treatment-related mortality accounted for a significant proportion of deaths (about



25%) in Colombian children with cancer. Most of these deaths were attributed to preventable causes, with sepsis being responsible for > 95% of treatment-related mortality nationwide in children who were in remission from their cancer. In response, and as a first problem to tackle in the roadmap, a horizontal transdisciplinary collaborative network was formed and strategies to reduce sepsis-related mortality were developed. Accordingly, pediatric oncologists, pediatric infectious disease specialists, pediatric critical care physicians, general pediatricians, primary care providers, and nurses from eight Colombian hospitals and academic centers joined together for the first time to embrace a shared objective. With support from the PanAmerican Health Organization (PAHO), and in alliance with the Colombian Ministry of Health, this team of key stakeholders met for the first time in 2024 to jointly analyze VIGICANCER data. Data-informed targets were then established to tackle sepsis as the most common actionable cause of treatment-related mortality. With this goal, a new transdisciplinary and cohesive team was formed called MANejo MULTidisciplinario para el Tratamiento de la neuTropenia febril y Sepsis, MAMUTTS® [Multidisciplinary

management for febrile neutropenia treatment and sepsis].

This nascent transdisciplinary network enables the design of targeted multilevel interventions to enhance high-quality care for Colombian children with cancer. Our ultimate goal is to reduce the number of years of life lost and to significantly enhance the health and future of Colombia.

This is a new model in Colombia, and our experience can be replicated in other low- and middle-income countries. VIGICANCER's systematic and meaningful results have positioned this unique surveillance system as a springboard for concerted collaboration among pediatric oncologists, allied clinicians, community stakeholders, and policy-makers, which will greatly benefit Colombian children. Our pioneering network constitutes a replicable model that serves as a platform for health equity, enabling progress in childhood cancer care. We celebrate with joy and gratitude Foundation-S 20th anniversary and we deeply thank Foundation-S for their support and access to global experts, which have been instrumental in the growth and impact of VIGICANCER.

When Innovation Meets Commitment



ONCOpeds and Early Cancer Diagnosis in Peru

By Liliana Vásquez

In Peru, geography can decide how quickly a child with cancer reaches treatment. Families in the Andes or the Amazon often travel hours or days to see a specialist. Until a few years ago, many children arrived at tertiary hospitals in Lima with advanced disease, after long diagnostic delays and repeated visits to primary care. Studies showed that the average latency to diagnosis was more than 100 days – over three times longer than in high-income countries – and that much of this delay was due to health-system factors such as lack of training, limited access to specialist consultation and slow referral pathways.

Against this backdrop, a small team of pediatric oncologists, engineers and public health professionals in Peru set out to design a simple but ambitious tool: a mobile application that would place pediatric oncology expertise directly in the hands of frontline providers. With seed funding from the My Child Matters programme of the Sanofi Espoir Foundation, they developed ONCOpeds® (Pediatric-Early-Diagnosis-System), a smartphone app to support early diagnosis and timely referral of children with suspected cancer. The app had an important impact by improving the referral pathway and facilitating rapid specialist input, ONCOpeds contributed to a notable reduction in referral time and

supported the recovery of essential pediatric oncology services. Building on this progress, Peru adopted a national strategy for timely detection, using the app's algorithm and clinical logic as a foundation. As a result, the country is now prioritizing early diagnosis as a national commitment and has already documented a reduction in time to diagnosis.

Building on this strategy, the Ministry of Health then moved to institutionalize and expand telemedicine tools, which evolved into TeleOnCopedes, now integrated into Peru's national TeleAtiendo telemedicine platform. Through this system, primary-care providers can initiate teleconsultations from the first level of care, receiving real-time guidance from pediatric oncology specialists. The goal is clear: strengthen the early identification of childhood cancer and ensure rapid, informed clinical decisions for children everywhere in the country. Implementation of TeleOnCopedes has already begun in Arequipa, Junín and La Libertad, three regions where early identification and timely referral remain essential to improving outcomes. The expansion marks an important step toward a decentralized, equitable model of care—one that ensures that even children in remote Andean or Amazonian communities can benefit from specialist expertise.

Aditya's Journey

Waiting for Hope

How

My Child Matters

By Eddy Supriyadi

Transformed Our
Journey in Childhood
Cancer Care



Living in a developing country like Indonesia, I discovered many challenges while treating children with cancer as a pediatric hemato-oncologist. I believe children with cancer have the right to receive the best care and treatment to improve their survival. When I first entered the world of pediatric oncology, I carried both hope and fear. Hope, because every child deserves a chance to heal; fear because I had seen too many come too late. In Indonesia, where resources and awareness are unevenly distributed, delayed diagnosis remains one of the biggest barriers to survival for children with cancer. Many arrive at tertiary hospitals when their disease has already advanced beyond what medicine alone can easily reverse.

I used to ask myself, "Why do so many children come too late?" The question haunted me during night shifts in the oncology ward. Parents would travel hundreds of kilometers, often after seeing several doctors, or traditional practitioners, before reaching our center. Some believed the swelling was an infection, others thought it was a curse. And by the time we established the correct diagnosis, the cancer had already spread.

That question became the seed of a research study. I wanted to understand the patterns, the causes, and the human stories behind diagnostic delay in childhood cancer. I wanted data that could help us intervene earlier, educate better, and perhaps, save lives.

Aditya was only four years old when his parents brought him to our hospital. He came from a small town, nearly eight hours away by road, referred by a regional hospital that suspected a serious blood disorder, possibly leukemia.

His father works as a construction laborer, earning barely two million rupiah a month serving his family (4 people). He had borrowed money from relatives just to afford the bus fare and food.

When Aditya arrived, he was pale and weak. His tiny hands were cold, and he had lost interest in playing or eating. After running some initial blood tests and looking at his blood smear under the microscope, our team became convinced that Aditya needed more basic-advanced lab tests: a bone marrow examination, morphology, cytochemistry and immunophenotyping to confirm the diagnosis. That was when the real challenge began.

Aditya's parents had never had health insurance before. They registered for BPJS, Indonesia's national health insurance, only when he was referred to our hospital. Unfortunately, the activation process would take up to 14 working days. That meant that for two long weeks, Aditya's diagnosis and any possible treatment had to wait.

For a child with suspected leukemia, everyday matters. But without active insurance, the family couldn't afford the

next steps. The father asked, almost whispering, "Can we pay little by little? I will find a way." It was a heartbreaking question not because of his inability to pay, but because of the injustice of waiting for paperwork while a child's life hung in the balance.



The medical team did what they could to stabilize Aditya, managing his symptoms, and preparing for tests but the clock kept ticking, and sent Aditya to the guest house to wait for the BPJS activation process. Bureaucracy became an invisible barrier between illness and healing.

This story isn't just about one child; it's about many families facing the same reality. In Indonesia and other low- and middle-income countries, universal health coverage (UHC) like BPJS is a lifeline. It allows children from poor families to receive chemotherapy, transfusions, and hospital care they could never afford otherwise.

A child like Aditya doesn't have two extra weeks to spare. The delay, though procedural, can mean the difference between a treatable disease and an advanced, life-threatening condition.

When I saw MCM call for proposals focusing on early diagnosis, I knew this was exactly the kind of partnership

that could make a real difference in our community then I submitted a proposal.

Several weeks later, I received the email that changed everything: our project had been selected for support by **My Child Matters**.

Our study found that bureaucratic/system delays in insurance activation are among the hidden causes of late diagnosis in childhood leukemia. Parents want to save their children but sometimes, the system makes them wait too long.

When Aditya's BPJS finally became active, we wasted no time. The bone marrow test confirmed acute lymphoblastic leukemia, the most common childhood cancer but also one of the most curable if treated early.

Aditya started his chemotherapy within days. His mother stayed by his side every night, sleeping on a mat near the bed, while his father went back to his job to earn a little amount of money to support Aditya. Slowly, the color returned to his cheeks. The day he smiled again, the entire ward seemed brighter.

That moment was a reminder treatment works, but only if children can access it in time.



Lessons from Aditya

Aditya's story became part of our research on diagnostic delay and treatment access in children with cancer. It showed us that poverty is not the only barrier; administration, distance, and awareness all play powerful roles in shaping outcomes.

Months later, Aditya's father visited the ward again this time, smiling. He brought a small bag of fruit for the nurses and said softly, "Thank you for not giving up on us."

He now volunteers to help other families from rural areas who face similar struggles. "When you are poor," he said, "you think hospitals are not for people like us. But now I know help is there. We just need to reach it in time."

Through the efforts of My Child Matters and our national pediatric oncology team, we are learning that saving a child's life is not only about medicine; it's about making care accessible, affordable, and timely. Aditya's journey reminds us that behind every statistic is a child with dreams to run, to play, to go to school again.

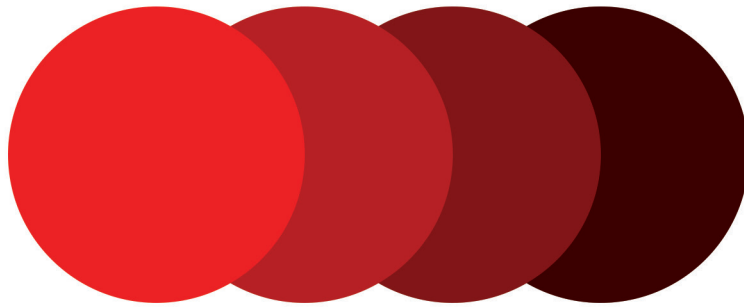




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the chance
to live without
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