TOGETHER WE CREATE
A SUSTAINABLE IMPACT

My Child Matters
Fighting childhood cancer in countries with limited resources

The Sanofi Espoir Foundation thanks its partners, mainly St Jude Children’s hospital, SIOP, UICC, GFAOP and CCI, for joining it in a socially responsible approach to the sustainable reduction of childhood cancer inequalities.
Improving the survival rates of children with cancer

The number of children who have to struggle with cancer is not known because most of them are undiagnosed. It is estimated each year that approximately 175,000 children are diagnosed with cancer and 90,000 of these will die from the disease. With prompt and effective treatment most childhood cancers are curable – but global statistics expose a shocking disparity – the five-year survival rate for children diagnosed with cancer in developed countries is 80%, but this rate falls to an average of 40% or even 20% in low-resource countries where it is difficult to gain access to information, early diagnosis, care or treatment.

As a way of addressing this inequality, the Sanofi Espoir Foundation conceived of the My Child Matters (MCM) program for low-resource countries to combine financial support, aid from international experts, networking and sharing of experiences, as well as annual reviews by an expert committee consisting of pediatric oncology professionals, and MCM executive members. The key partners in the development of MCM program by Sanofi Espoir Foundation are experts from the St. Jude Children’s Research Hospital and representatives of organizations such as SIOP(1), UICC(2), GFAOP(3) and CCI(4).

My Child Matters is based on the premise that improvements to healthcare infrastructure, training of qualified personnel, raising public awareness, better access to quality and palliative care, giving psychological support to children, families and caregivers whilst involving local governments are the key drivers in an integrated approach to improving children’s chances of surviving cancer.

Since 2006, 45 projects in 33 countries have received support. Today, 13 projects in 26 countries continue to benefit from this initiative and over the past nine years there have been several successful projects. For example Cali, Colombia established the first childhood cancer registry. The initiative in Paraguay brought cancer care for children closer to home, meaning they were less likely to abandon their treatment. These are just two examples of the many improvements in cancer management and outcomes as a result of MCM initiatives that can be read about here.

WHAT ARE THE BIGGEST CHALLENGES IN FIGHTING AGAINST CHILDHOOD CANCER IN DEVELOPING COUNTRIES?

- Childhood Cancer is often detected too late.
- There is an insufficient number of well-trained healthcare professionals to provide treatment.
- Appropriate treatment is often unavailable or not affordable.
- Pain management and palliative care are very limited.
- Childhood cancer is often not a health priority.

The national goal in every country concerned is to help strengthen the healthcare system and influence public health policies.

(1) International Society of Paediatric Oncology
(2) Union for International Cancer Control
(3) Groupe Franco-Africain d’Oncologie Pédiatrique
(4) Childhood Cancer International
Worldwide about 175,000 children develop cancer every year. 80% of these new cancer patients live in developing countries where only 20-40% are expected to survive as compared to more than 80% survival in the developed world. Estimates of these global figures come from population based cancer registries that collect data on the occurrence of all new cancers, and their ultimate outcome. However there are wide disparities between the existence of cancer registries in the developed and the developing countries, and this is especially evident in the registration of childhood cancer. Childhood cancer is highly treatable and so one of the most important uses of these registries is the data they generate, as this can then provide evidence to guide strategy planning to effectively control cancer and treatment outcome.

Cali is the second largest city in Colombia and houses the oldest cancer registry in Latin America, the Cali Cancer Registry (CCR), which has existed since the early 1960’s. The CCR is the only real-time cancer surveillance system in all of Latin America. CCR is primarily an adult cancer registry which has also been gathering some basic incidence and survival data for children over the years. It was observed that the outcome of childhood cancers had failed to improve in the last 3-4 decades even though there had been substantial improvements in the available healthcare facilities and uniformly free cancer therapy. So a group of pediatric cancer doctors decided to develop Colombia’s first formal childhood cancer outcomes surveillance system called “Vigicancer”, to help them understand the reasons behind this lack of outcome improvement. The Vigicancer was established in 2009 with the support of My Child Matters (MCM) program. Within the first 3 years of this project starting the Vigicancer results showed that the treatment outcome for patients who had public/government insurance was much worse compared to patients who had private insurance, even though both types of patients were treated with exactly the same treatment plan. This disparity was a result of the slow process of authorizing the funding for chemotherapy and other treatments by the public insurance plan. As a result, significant delays occurred before every course of treatment, leading to a substantial increase in the chances of the therapy failing. The results also showed that patients with public health insurance were ten times more likely to abandon treatment (20.8% versus 2.8%) compared to patients with private health insurance; this also affected the overall disease survival. As this discovery shows, the development of a specific pediatric cancer surveillance system in the tumor registry yielded crucial information that could help guide future health policy decisions.

Based on the results from these first three years, the country’s health authorities are now investing in improvements to the public health insurance system, and they are also considering at a national level various ways of helping to decrease the numbers of people abandoning treatment. So after more than 30 years of stagnation, the future of childhood cancer outcome in Colombia has suddenly brightened. The results of the Vigicancer project have clearly engaged the government’s attention and shown the authorities what they need to do to create a lasting impact. This project can therefore be seen as a good model for duplication in other developing countries that are seeking answers to similar questions.
Paraguay

Bringing childhood cancer care closer to home to encourage families to complete treatment

Childhood cancer is curable if diagnosed early and treatment completed.

In Paraguay, childhood cancer is the second leading cause of death amongst children, and each year almost 400 children are diagnosed with this dreaded disease. The Pediatric Cancer Center at the School of Medicine in Asuncion is the national referral center for children with cancer and deals with more than half of the country’s total number of children under eighteen with cancer. Up until 2008, most of these children were already beyond help by the time they arrived. There was also a high rate of treatment abandonment because of the difficulties faced by families, who had to travel vast distances to reach this hospital for therapies that have to be continued over months, often years. This is particularly distressing when you realize that almost 80% cancers in children are curable if diagnosed early, and treated promptly.

This situation began to change in 2009 when Dr. Angelica Samudio, head of the Pediatric Cancer Center, put forward a project that aimed to create a network of satellite clinics spread across the main regions from where patients were referred to the cancer center. This was called the Childhood Cancer Care Network (Red Nacional para la Atención al Cancer Infantil or ReNACI). This would provide a local facility in each region, which patients could easily get to without having to travel long distances. The project planned to educate the public about tell-tale signs that could suggest cancer to enable them to walk in with the earliest warnings of the disease. This included training local doctors and nurses to recognize early signs of cancer, but also crucially improving their expertise in delivering cancer chemotherapy and ongoing patient care, to allow patients to continue their therapy closer to home after initial diagnosis, and thus reducing chances of patients abandoning treatment. The ultimate goal of the project was to improve outcomes through efforts to catch the disease early and ensure treatment completion.

Support provided by the My Child Matters (MCM) Program helped initiate this project, whose public health impact attracted the attention of the government so rapidly that the Paraguayan President declared it a project of National interest through a decree issued in 2009. By 2011, the Ministry of Health was sufficiently motivated to begin implementation of the National Cancer Control Program. This recognition helped the ReNACI network obtain two major grants that converted the childhood cancer unit in Asuncion into a regional center of excellence with state-of-the-art diagnostic capability for acute leukemia, the commonest cancer of childhood. In 2012, the Paraguayan government announced financial aid for childhood cancer treatment in the national budget through the National Fund for Solidarity Resources for Health (FONARESS) law.

This is a wonderful example of the successful development of a robust, sustainable national program that came about as a result of the initial dedication and commitment of local leaders who carefully designed an impactful project, and who were then supported by the timely financial assistance provided for its initiation by the MCM program. They have since produced impressive results thanks to the impetus provided by the country’s government through formal recognition, support, and future funding.
Senegal

A holistic approach to improving childhood cancer care

Senegal has a population of 12.5 million, about 40% or 5 million of whom are children under the age of fifteen. Like most sub-Saharan African countries, the most common causes of death for children in Senegal are infections like malaria or AIDS. Cancer, though devastating, does not contribute significantly to the numbers of childhood deaths, which is why there wasn’t a dedicated medical service for children’s cancers even in the capital city, Dakar, until recently. In 2000 the need for this service was recognized, and a children’s cancer unit was created in the Aristide Le Dantec (ALD) Hospital, Dakar. The French African Pediatric Oncology Group (GFAOP) helped create this unit by developing adapted standard treatment plans for cancer treatment, and provided funding for free medication. This was certainly a step in the right direction but the available service still required a more holistic approach in order to achieve the best survival rates possible.

The survival rate for nephroblastoma, a common childhood kidney tumor, increased from 50% in 2006 to 74% today.

In 2005, Dr. Claude Moreira from the ALD Hospital put forward a request for support from My Child Matters (MCM) to initiate a project that aimed to reduce deaths caused by cancer treatments, especially those due to infections that develop as a result of low patient immunity during cancer therapy. The project addressed this issue at several levels: by aiming to improve early cancer diagnosis so patients could be treated with less toxic therapy; through better quality of supportive care and efficient management of problems like pain, fever, infections; through better training of healthcare staff; making patients and parents more knowledgeable about childhood cancers, and finally through the creation of more centers, so as to improve patient access to timely care, particularly in the peripheral parts of the country.

The GFAOP and the Senegalese government wholeheartedly supported the project and their backing has been a key element in the project’s immense success in under a decade. The survival rate for nephroblastoma, a common childhood kidney tumor, increased from 50% in 2006 to 74% today, similarly survival for lymph node cancers has improved from 40% to 71%, and for blood cancer from 45% to 59%. The cost of therapy, including surgical procedures, is entirely borne by the government, so no child is deprived of treatment because their families can’t afford it. The latest figures for patients failing to return for their follow up have decreased from 22.6% previously to 6.6% today.

The ongoing projects in Senegal include decentralization of childhood cancer care to ensure treatment delivery closer to the children’s homes, extension and capacity building of the pediatric oncology unit in the ALD Hospital, and the development of a cancer registry so that data about childhood cancer can be more accurately collected. It is a tremendous success to have gone from nonexistent pediatric cancer facilities to the creation of a stable, well established national service that continues to grow and develop, and indicates that there is a very bright future for childhood cancer care in Senegal.
It was only in the 1990s that the necessity of training specialist pediatric doctors and nurses for childhood cancer was first recognized in the Philippines. However, by 2006 the country had already produced 20 well-trained pediatric cancer doctors through the concerted efforts of a handful of dedicated pediatric oncologists.

This was a vast improvement on the previous situation when only adult cancer specialists were available to treat children’s cancers. Even despite this improvement in medical professionals’ expertise, the outcome of childhood treatment remained dismal with only 16% of the children surviving long term in the Philippines, as opposed to more than 80% overall survival for the same diseases in the developed world. The reasons for this poor outcome were the delay in diagnosis, as 70% of the cancers were diagnosed at an advanced stage, and unaffordable treatment, forcing almost 80% of families to abandon their child’s therapy before completion.

In 2006 Dr. Julius Lecciones, one of the pioneers of pediatric oncology in the Philippines created an innovative demonstration project to raise public awareness about the curability of childhood cancer, and focus the government’s attention on this important public health issue. As well as raising awareness of both the public and professionals about early signs of cancer, the project also aimed to improve access to care by developing a network of satellite centres across the country, particularly in the peripheral, underserved areas. Additionally, this project hoped to encourage local funding agencies to assist families in paying for their child’s treatment. This endeavour was therefore a perfect fit for Sanofi Espoir Foundation’s My Child Matters (MCM) Program whose mission is to help reduce inequalities in the care of childhood cancer worldwide. MCM began funding this project in 2006 and has continued to do so even as the seed that was sown then has since blossomed into a strong, self-sustaining tree.

Nine years later, in 2014, the survival rate for childhood blood cancer, the most common cancer in children, has improved from 16% at baseline to 78%, and the percentage of families abandoning treatment has fallen from 80% to 5%. Even in this short time, the combined effect of better public awareness of the first signs of cancer and the ability of doctors to correctly and efficiently diagnose the disease has helped decrease the percentage of children with advanced stage cancer at diagnosis from 70% to 30%.

The secret of the amazing success and sustenance of this project undoubtedly lies in the recognition and support it gained from the country’s local government and funding agencies. The project therefore shows the importance of active advocacy campaigns in improving childhood cancer care worldwide.

**Philippines**

Improving childhood cancer care and the outcome for childhood blood cancer.

![Children playing with volunteers in the hospital.](image1)

![Dr. Julius Lecciones and his team with some of the children they treat.](image2)

![Image 3](image3)
rain tumors, often called central nervous system tumors, comprise the second largest category of all childhood cancers worldwide, after acute leukemia. However, unlike children with acute leukemia who often benefit from widely successful modern treatments, treating children with brain tumors remains a major challenge even in the best centers of the world. Successful management of brain tumors requires that experts from many fields – neurosurgeons, anatomic pathologists, pediatric and radiation oncologists, radiologists, and rehabilitation service specialists – come together to develop a unique plan of care for each patient. In countries with limited resources where there is a lack of adequate funds, expertise, infrastructure, and professional personnel, it is often very complicated to bring a multidisciplinary team like this together. Yet it is possible, as was demonstrated beautifully by a project supported by the My Child Matters (MCM) program in Thailand.

Thailand is divided into four regions: North, North-East, Central, and South, and consists of 20 provinces. In 2009, several key experts in childhood cancers coordinated a nationwide survey to determine the resources available to treat brain tumors across Thailand. Soon after, MCM provided funding that allowed project coordinators to expand this project to become a national network of brain tumor care. The Thailand Pediatric Oncology Group (Thai POG) established effective cooperation between existing facilities and experts by creating guidelines for collaboration, patient referral, and training health professionals. Another important step taken by the Thai POG, with MCM support, was to establish the first pediatric brain tumor registry in Thailand. Currently, they are drafting guidelines for uniform pathology reporting, developing a consensus on standardized treatment protocols, and creating regional neurosurgical centers.

This project has garnered attention from the Thai government, a significant indicator of the project’s success and sustainability, and ultimately the goal for all MCM Projects. The government is interested in establishing a clear system of payment for brain tumor patients, as well as allocating resources in the form of payment packages for managing individual tumor types.

What began as a survey assessing brain tumor treatment resources has evolved into a robust national collaborative network. As a result there are wonderful prospects within this network for an efficient patient referral system, optimal utilization of available diagnostic and therapeutic facilities, and multidisciplinary care.
Thailand

“From Cure to Care” – striving to make better quality of life a priority for both patient and family

Childhood is a symbol of life, hope, and happiness. Death, dying, and cancer are words not typically associated with children. Thus when parents are confronted with a cancer diagnosis for their child, they are terrified by their new reality, as well as having to battle practical considerations such as the expense of treatment, travel and finding new accommodation close to the hospital. An innovative project at the Songklanagarind Hospital is helping to lessen this burden for families and thus ensure that pediatric oncology patients receive full treatment.

Songklanagarind Hospital is the largest cancer Hospital in the southern part of Thailand and is linked with the Prince of Songkla University. Eighty percent of all children seeking cancer treatment at Songklanagarind Hospital come from other provinces. While the government covers a portion of the treatment costs, families often struggle to afford travel and accommodation, leading them to abandon treatment. Fortunately, Dr. Pornpun Sripomsawan, a young, energetic childhood cancer doctor, recognizes that a pediatric cancer diagnosis devastates the whole family. She feels for her young patients with the heart and mind of a parent, naturally understanding that the intricacies involved in treating one child with cancer will necessarily have ramifications for all the family. Dr. Pornpun conceptualized an innovative approach to address these challenges, and with the help of My Child Matters program in 2009, put into action “From Cure to Care,” a multi-faceted project to make life a little easier for those families whose children have a cancer diagnosis. First, she arranged for families to have a “home away from home” by providing temporary housing near the hospital, at no extra cost. She also implemented a 24-hour nurse hotline for emergencies, reassuring parents that help is always at hand. She also started another program called the “school for sick children,” allowing children to continue their education during their cancer treatment. Additionally, the “friends of friends” program puts newly diagnosed cancer patients in contact with teenage cancer survivors, whose empathy and shared life experiences create a natural bond of trust and lasting friendship, and helps young patients cope with their grief and anger. Finally, the “Happy Friday” initiative and the Cure2Care website have attracted many volunteers, generating widespread awareness and interest in the welfare of children with cancer.

Just two years after the start of the project, more than 250 young cancer patients had benefited from school education during therapy, and more than 20 children had participated in cancer kids camps. The treatment abandonment rate had fallen to zero, and there was a documented decrease in the risk of children succumbing to infections, due in large part to access to clean housing and prompt treatment of early signs of infection.

The NHSO awarded the Southern Childhood Cancer Network a Certificate of Merit in December 2012 for the best national network, and has expressed support for the project by awarding a grant for it to continue its mission.

The project’s success has attracted attention from the National Security Health Office (NHSO), the main health authority that pays for medical expenses in government hospitals. The NHSO awarded the Southern Childhood Cancer Network a Certificate of Merit in December 2012 for the best national network, and has expressed support for the project by awarding a grant to continue its mission. Their recognition promises a path of sustained growth and development of this holistic approach to cancer care.

In the Pediatric Department there is a focus on the palliative care of children as part of a holistic approach to treating childhood cancer.

C

The NHSO awarded the Southern Childhood Cancer Network a Certificate of Merit in December 2012 for the best national network, and has expressed support for the project by awarding a grant for it to continue its mission.

The project’s success has attracted attention from the National Security Health Office (NHSO), the main health authority that pays for medical expenses in government hospitals. The NHSO awarded the Southern Childhood Cancer Network a Certificate of Merit in December 2012 for the best national network, and has expressed support for the project by awarding a grant to continue its mission. Their recognition promises a path of sustained growth and development of this holistic approach to cancer care.
To improve survival of children with cancer through early detection at primary care and community levels, utilizing the IMCI (Integrated Management of Childhood Illnesses) tool. This MCM supported project is being coordinated by PAHO (Pan American Health Organization) in collaboration with each country’s Ministry of Health. The project aims to improve outcomes for childhood cancer by validating and implementing a locally developed methodology for detecting early signs of childhood cancer. The pilot project is being conducted in Colombia and Honduras with the intention of developing it into a model that can be replicated in other Southern and Central American countries.

**Honduras**

At the newly formed Mario Catarino Rivas Hospital in San Pedro Sula, teaching and training of nurses, doctors and other healthcare professionals has been initiated to create the necessary expertise to provide comprehensive childhood cancer care. The Mario Catarino Rivas Hospital has the potential to be a childhood cancer referral center but because of financial constraints it is unable to hire the necessary experts. MCM is currently supporting a project which has an educational approach to capacity building, improving the expertise of the existing staff through teaching and training.

**Guatemala**

Creation, development and validation of a Pediatric Palliative Care Nurse Education Program. This project is being implemented at the UNOP (Unidad Nacional de Oncología Pediátrica) Hospital, a specialized pediatric oncology hospital. The aim is to establish an accredited nurse training program to improve the standard of symptom management and patient care coordination not only in Guatemala, but also in other Central American countries and beyond.

“MCM program’s unique approach, of empowering project sites through autonomy over utilization of project funds and assigning project-specific experts as mentors, helps create unparalleled opportunities for growth and development of local leaders and advocates.”

Alia Zaidi, Medical Director of My Child Matters program.

**LATIN AMERICA**

**Colombia and Honduras**

Early detection improves children’s survival rate.
Pakistan

Local collaboration for pediatric oncology capacity building in Pakistan.

Pakistan is the sixth most populous country in the World and children comprise 34% of its estimated 190 million population. There are only 14 pediatric centers for this huge pediatric population that claim they are capable of treating childhood cancer, and these have widely varying levels of expertise. MCM is currently supporting two projects in Pakistan which together aim to increase expertise and physical capacity for management of cancer in children. The two projects complement each other, working collaboratively to enhance the capability nationwide of treating childhood cancer.

One is a pilot project which aims to develop the first pediatric oncology shared care unit in the country, and the other supplements it by providing training and education to nurses, pediatricians and general physicians. Two pediatric oncologists based in Karachi and Lahore, the two largest cities in the country, jointly coordinate these projects.

Thailand

Creating a regional collaborative network for palliative care in Thailand.

Although Thailand has an established network of physicians who consult and collaborate in the management of childhood cancers called the Thai Pediatric Oncology group, this network lacks an established palliative care service for children with cancer. Since the country has a large rural population, many children with non-curable or advanced disease experience great difficulty in finding support to manage their symptoms towards the end of their lives, outside of the setting of a major hospital. The project currently sponsored by MCM in Thailand aims to create a nationwide collaboration between cancer centers to increase availability and facilitate accessibility of palliative care throughout the Kingdom of Thailand.

"Setting up regional networks, creating and promoting local leadership will assure the future of the My Child Matters program."

Dr. Raoul Ribeiro, President of My Child Matters Executive Committee
Our projects throughout the world since 2006
Working in partnership

Why did you decide to fight against Childhood Cancer?

Caty Forget. In countries with limited resources, childhood cancers have long been a neglected battle, silent but deadly, as attention and priority are given to transmissible illnesses like malaria, diarrhea or respiratory infections. As a result there is still an intolerable disparity between a child’s chances of survival in an industrialized country and in one with limited resources where the diagnosis is made late, with an insufficient number of well-trained professionals and where care is difficult to access. We can make a change by investing in the future as childhood cancers need not be fatal. Most of them are curable if diagnosed early and treated in time. Part of the solution to this relies on financial resources, but first of all it is a question of political willingness and a shared sense of responsibility to put childhood cancer on the agenda. This is why we conceived the My Child Matters initiative to address this inequality and help low-income countries in Africa, Asia and Latin America fighting childhood cancer.

How did you choose which projects to support?

Anne Gagnepain-Lacheteau. The projects currently being carried out in the field were selected following a call for proposals for three-year initiatives.

The «My Child Matters» program enables local pediatric oncology teams to benefit not only from financial support but also from international experts in pediatric oncology and public health. This program has been implemented in countries where there is a dynamic pediatric oncology team capable of building lasting partnerships with various local stakeholders.

The My Child Matters initiative provides one of only a very few avenues for advancing pediatric oncology in low- and middle-income countries (LMIC). Since its inception in 2005, pediatric cancer advocates in the developing world have turned to My Child Matters for grants to assist in developing programs aimed at improving the pediatric cancer outcome in their regions. With several years of operation, My Child Matters (MCM) has shown the world that it is possible to make a difference in areas with limited resources. Yet, there is still a lot to be done.

The challenges faced in LMIC are common and include lack of chemotherapy, abandonment of treatment due to distance from home to hospital, fragmented health care services, lack of health personnel trained to recognize signs and symptoms of cancer early, inability to pay expenses of treating cancer, pain caused by cancer, treatment-related toxicity and many more. However, while most developing countries share common challenges, each has its own specific hurdles to overcome. These barriers. Importantly, successful MCM projects are those that have Project Leaders who work tirelessly to meet their stated objectives in overcoming some of these barriers, ultimately leading to improved prospects for childhood cancer patients.

Further, successful MCM cancer control projects include MCM mentorship from various experts and seed money to initiate pediatric oncology work in the right direction. The goals are program growth and self-sustainability. These can be achieved by establishing support from local, national and international sources. In fact, one of the most important aspects for enhancing childhood cancer control in a country is garnering the support of health authorities for treating children with cancer. Support for pediatric cancer in LMIC is often ignored, because of fierce competition for funding from worldwide efforts and attention toward improving infectious disease rates. However, given the vast improvements in pediatric cancer survival rates in the developed world, it is clear that most pediatric cancers can be cured when detected early and treated appropriately. No child should have to die of cancer when effective treatments are available. It is imperative that health authorities recognize this and take steps to ensure that all children with cancer are properly diagnosed and treated. Each barrier to achieving improved survival rates can be addressed with the aid of health authorities, and I am excited to share with you that many of our coordinators have made this possible by demonstrating the value of their work with concrete measures.

How does this My Child Matters program relate to the global strategy of the Sanofi Espoir Foundation?

Caty Forget. Our Foundation is dedicated to the sustainable reduction of healthcare inequalities amongst communities with the greatest need. To meet this goal, we decided to concentrate our efforts on three areas, in which we have developed strong networks of expertise: firstly to fight childhood cancer; secondly to reduce maternal and neonatal mortality, and lastly to improve access to healthcare for the most vulnerable patients.

My Child Matters’ initiative illustrates the Foundation’s DNA to nurture long term partnerships by addressing key issues in prevention, training and access to care so as to impact on capacity building and development, and reduce the vicious disease-poverty circle.