

Sanar Case (English Version)

The Sanar Niños con Cáncer Foundation is a nonprofit organization with 30 years of work in Colombia that gives comprehensive assistance to children and adolescents with cancer and their families without any distinction of race, origin, nationality or economic situation, prioritizing the cases of greatest vulnerability. It has provided assistance to more than 15.000 children with cancer in the country, impacting the survival life rates of this population. With the implementation of an in-hospital and out-of-hospital monitoring model integrated with the work carried out by the medical team in the partner hospitals, the foundation is committed to decrease treatment abandonment, promote the adherence to it and influence the childhood cancer survival rates.

OUR INSTITUTION

The idea of SANAR arose on February 27th, 1985, from the urgent need to help hundreds of children diagnosed whose greatest barrier for survival was the lack of resources to acquire these drugs. Thus, thanks to a group of people who shared a similar and close experience with this illness, in July of the following year, the creation of SANAR Association for the prevention and treatment of cancer in children was made official by means of registration with the Ministry of Health which is known today as FUNDACIÓN SANAR NIÑOS CON CÁNCER. Mr. Luis Guillermo Angel (current president of the Foundation), Mrs. Claudia Gaitán de Caballero (current member of the board of directors), Mrs. María Victoria Ortiz (RIP) and Mrs. María Teresa Toulemonde (RIP) collaborated with Doctor and scientist Fabio Restrepo Ángel, (RIP), who for more than 60 years dedicated his professional life to relieve children with cancer and provide them with the necessary means to overcome this illness efficiently.

From the first moment, Sanar's social challenge was to provide the adequate, timely and constant care to Colombian boys and girls with cancer with a greater emphasis on those lacking the resources to assume a highly expensive healing process. This is the way Sanar began its work supporting the procurement of oncological drugs and the provision of chemotherapy rooms in hospitals such as Hospital Lorencita Villegas de Santos and Hospital de La Misericordia .This work also identified the need and importance of psychological and social support for both boys and girls and their caregivers and thus began what is known today as the missionary programs of Sanar.

With the permanent support of all sectors during its first years, the foundation offered children with cancer the latest advances in science, surgery, radiotherapy, chemotherapy and the dedication and delicate care of experts in the different areas of health involved.

During its first years, it was a witness and protagonist of a process in which great advances were made from the scientific point of view, and there were significant changes in the management, control and cure of cancer in children.

To mention some of them, 37 years ago the greatest obstacle in the healing of Colombian children was the high cost of medicines plus the difficulty in acquiring them. Very few people could import them. Therefore, one of the objectives of SANAR was to have a bank of neoplastic drugs that would facilitate treatment without interruption, and the support of different pediatric university centers in the country, to provide children with hospitalization, surgery and radiotherapy.

In many children's hospitals like the Niño Jesús Hospital in Barranquilla, La Misericordia Hospital, the Lorencita Villegas Hospital in Bogotá until the last moment, San Jorge Hospital in Pereira, Erasmo Meoz in Cúcuta, and the Santander University Hospital in Bucaramanga, the little patients received the most advanced care available worldwide and in several of these centers SANAR built modern and exclusive pavilions for them.

A very valuable resource for children was the free access to radiotherapy and to professional care in the Carlos Ardilla Lule Oncology Institute of the Santafé Foundation, with which SANAR signed an agreement by which since 1987, many children have been taken care of and thousands of leukemia immunity studies have been carried out for families that cannot afford them.

From its beginning, SANAR has known how to adapt to the challenges that modernity poses and to the new approaches on social medicine which allows it to guarantee the excellence and timeliness of its services.

In June 2018, Sanar signed a collaboration agreement with the National Cancer Institute to work together in favor of the comprehensive care of children and young people with cancer who receive treatment there.

From the year 2020 and during the year 2021 the Foundation actively participated in the project "Integrated Initiative for Cancer Control in Latin America". This study was led by the International Union for Cancer Control – UICC- and the Harvard University School of Public Health. Sanar was part of the local committee of the study for Colombia alongside allies such as the National Cancerology Institute, the Colombian League against Cancer, the Javeriana University, the San Ignacio Hospital and the Simón Foundation. The final document offers 9 recommendations to face the challenges that Colombia faces in the subject of cancer and can be consulted on the UICC page at the link: www.bit.ly/3dbYgjl

SANAR NATION WIDE

Since 2008 SANAR was established as Fundación SANAR with the influence and the possibility of reaching all the departments of the country.

Presently, SANAR functions in Bogotá and supports patients from this city and those from other departments of the country, even though the main part of the diagnoses and treatment centers are located in the main cities. Attached is a descriptive report of the socioeconomic characteristics of the population that the Foundation benefits.

SANAR also has 3 branch centers in Barranquilla, Pereira and Bucaramanga and even though they are independent in their constitution and legal recognition, they develop the mission and objectives of SANAR and treat patients from nearby municipalities and cities.

NETWORKS TO WHICH SANAR BELONGS

At a national and international level, SANAR participates in support networks, training and incidence on the subject of child cancer, as follows:

National Networks:

- **Representative of NGO's at a National level in the National Advisory Council on Child Cancer:** As representatives of the NGOs at a national level we are the voice of the organizations that work in support of childhood cancer assisting the Council plan and contributing with knowledge and experience in training areas developed by the Ministry. From 2016 to 2019, we assumed the technical secretary of this area supporting the communication and the articulation of the actions of **NAC AI** for its efficient development.

- **Active Founding Member of Inter-Institutional Observatory of Childhood Cancer OICI:** As Founding Members and part of the Board of Directors we participate in the activities developed by the Inter-Institutional Observatory of childhood Cancer in the areas of education and training, contributing to educational conferences that promote early detection of childhood cancer at a national level, developing studies for the visibility and actions against access barriers in the care of children with cancer and providing information for the follow-up of cases that need more specific interventions to respond to timely and quality care.

International Networks:

- **Member of Childhood Cancer International, an organization of parents of children with Cancer CCI:** We are members of the Board of Directors for Latin America and work every year on the development of the annual training event on this platform, assisting the development agenda, sharing and participating with strategic issues that strengthen organizations and giving assistance in organizational strengthening of member Foundations.

- **Member of Latin Alliance, a support platform for organizations that work with chronic diseases:** We are part of this platform of Latin-American organizations that support chronic diseases participating and working in the Commitment Program that establishes 10 annual strategic actions for the consolidation of the network.

PRIZES AND RECOGNITION

- **1994:** National Solidarity Prize given by El Colombiano newspaper.
- **2004:** Solidarity prize mention given by the Alejandro Ángel Escobar Foundation.
- **2009:** First Place in the category "Support to Patients" in the Latin Excellence Prizes supported by the American Cancer Society.
- **2013:** Guinness World Records: largest quantity of collected and weighed plastic covers in 8 hours 156 tons.
- **2014:** Guinness World Records: Together with Garragan Hospital in Argentina: largest quantity of collected and weighed plastic covers in 8 hours. 477 tons.
- **2015:** Order of the Colombian Congress in the rank of Commander for altruistic work and for the trajectory in favor of children suffering from cancer awarded by the Honorable Congress of the Republic.
- **2016:** Green Latin America Awards in the solid waste category for the "Covers for Healing" Campaign a strategy of financial sustainability.
Versión 5-0 de junio 17 de 2021.
- **2017:** Good Citizen Prize, given by Bancolombia-Cívico with the support of City TV.
- **2018:** Mention in Solidarity Prizes Alejandro Ángel Escobar Foundation.
- **2019:** Social Recognition by the regional board and the National Board of the Accreditation System of Civil Society Organizations led by the Colombian Confederation of NGOs -CCNGOs.
- **2021:** Social Value prize mention given by Cepsa Foundation.

THE CHALLENGE OF CANCER

In developed countries the survival rate of patients with cancer under the age of 18 is of approximately 80%, but in most countries with a medium income the survival rate hardly reaches a rate of 50%.

In Colombia, child cancer is the second death cause in children between 5 and 15 years of age, and consequently, since the year 2008 this pathology is recognized as a public health issue due to its social impact and high mortality rates. By the year 2010 the Colombian Ministry of Health issued Law 1388 of 2010 that seeks to significantly reduce the cancer death rate in children and people under the age of 18 through the guarantee given by social security companies of all the services they require for the early detection and comprehensive treatment, application of protocols and standardized assistance guides and having the infrastructure, provisions, human resources and technology required in Specialized Centers enabled for this purpose. The law is by itself very complete, but nevertheless, its implementation and regulation has been slow and 10 years later we still have problems, barriers to access treatments, and shortcomings regarding comprehensive and quality care. Now the challenge is not about getting the medicines, now it is about getting children with cancer to access timely the comprehensive treatment to which they are entitled by law. On one hand, the patient's family and the community in general have to be educated, so that they know what their rights are and can enforce them, and also the law is weak regarding the emotional support that patient's families should receive, reducing the issue to foster homes and mere assistance aids.

The reality is that despite the fact that in Colombia there is Law 1338 and Law 2026 (Jacobo Law) according to which children with cancer are cared for in a timely and comprehensive manner, there are still many barriers that this population has to face to have access to treatment. On one hand, there are administrative barriers in the health system, but also the social, economic and cultural condition of the patients' families sometimes become a barrier that makes it difficult to give treatments with the frequency and timeliness that is required so that these children's lives are not at risk. **The missionary programs of the Foundation specifically seek that patients have timely and uninterrupted access to treatment in care centers and therefore have a greater chance of healing through actions such as:**

- Education and guidance of the care givers of these patients so that they can overcome the administrative barriers they face in their health care institutions.
- Financial support for transportation, food, accommodation, medicines, exams and medical supplies so that no treatment is interrupted due to financial difficulties.
- Follow up of patients during treatment and control to avoid drop outs.
- Therapeutic individual and group activities aimed at patients and care givers for a better comprehension of the disease and its treatment, by providing coping tools for the different stages of the pathology, and consequently generating adherence to the treatment.
- Occupational therapy activities aimed at patients and their families.

During the contingency of Coronavirus (2020-2021), SANAR's missionary programs continued operating, guaranteeing the assistance of boys, girls and adolescents with

cancer and their families who more than ever required the support of the foundation. During this time, the support was carried out virtually, but as of September 2021, face-to-face attendance was resumed at the National Cancer Institute.

THE TRANSFORMATION OF THE LIVES OF FAMILIES AND THE RESTORATION OF HOPE

The path that SANAR follows is to assist boys, girls and adolescents with cancer and their families so that they can show they count with a family and friendship ties that make it possible to heal life, beyond healing cancer.

SANAR recognizes cancer as an experience of life and not death, as a process from which it is possible to emerge strengthened as an individual and as a family independently from the outcome.

For this reason, SANAR's assistance model, seeks that each child and his family understand the process and that despite of the illness, life goes on, and that our children must continue playing, studying, dreaming, being children and on the other hand the care takers must continue with their life projects, because sooner or later the illness will pass and in this sense, life must continue. This way, it will be possible to give a new meaning to life and transform hope from the cancer experience, as long as the illness is assumed as an excuse, as a way to affirm and give a meaning to life.

According to SANAR's Founder, Dr. Fabio Restrepo Angel (RIP) those who assume cancer as a way of self-knowledge and self-discovery, to heal life, have learned that: **“Cancer is limited. It does not erode love. It does not end hope. It does not undermine faith. It does not compromise peace. It does not destroy friendship. It does not erase memories. It does not diminish courage. It does not invade the soul. It does not eliminate transcendence. It does not silence the spirit.”**

TESTIMONIALS

“On March 20th, 2019, my daughter Cristiannys who is 1 year old began chemotherapy. She has a hepatic blastoma. After a medical meeting the doctors decided that a liver transplant should be done and since in the Cancer Institute, they do not do that type of transplant, they gave me an order for Fundación Cardio Infantil. From that moment I began the process of authorizing the order. I waited for 6 months for my Health Care Institution to authorize it. SANAR Foundation guided me throughout the process. I filed a complaint with the Health Superintendence and also a legal petition and a second legal petition. My Health Care Institution sent me to a hospital in Soacha where they did not take care of oncological children. I was very desperate and SANAR Foundation paid my first appointment at the Cardio Infantil Foundation. There, the doctor told me that the only hope of life for my daughter was a liver transplant. I took that medical record to my Health Care Institution called Capital Health and they did not authorize the order. The last thing I had to do with the help of SANAR was a video where I explained my daughter's situation. SANAR Foundation

published the video in Social networks. I finally collected the money to pay the Cardio Infantil Foundation. After many inconveniences my daughter received the liver transplant and she is currently in treatment. Thanks to SANAR for their love and support.”

“My son who is 11 years old has been on a cancer treatment for 2 years and one month. His diagnosis is a high risk LLA. A year and five months ago he received a bone marrow transplant and a month ago he had a testicular relapse. All along this process SANAR has helped me far too much in all the areas of my life. I have received psychological support, social support, recreation, and empowerment. I attended small meetings where they gave me information about authorization rights and other important issues. But I would like to comment on something that is very important: since I have had to stay in the hospital for so long, I could not have a stable job, so SANAR has supported me 100%. They have helped me with transportation, food, rent, transfers to improve my son’s life quality. The foundation is a real family, it is a work team that helps children and their families. We, as all the families that are part of this Foundation are fortunate and blessed. Thanks to my SANAR family who is always there.”

“We arrived in Bogotá from Venezuela in the month of August 2017. In December of the same year my son was diagnosed with a Wilms Tumor. In Hospital de La Misericordia I heard of SANAR Foundation. Many thanks to this Foundation’s work team who supported me from the beginning of my son’s disease and gave me a helping hand. I thank God, the Social Worker and the Psychologist of SANAR for each of the experiences. Today, two and a half years have gone by. It was a tough process but my son who is now 11 years old, has finished his treatment, is currently going to school and I feel more at ease.



There are not enough words to describe all the help I received from SANAR, I am sincerely very grateful because even though it was a very tough process, my son had

many lovely experiences like the trip to San Andrés with all his friends. They had a lot of fun, took many pictures played a lot...for him it was an unforgettable experience.”

“I was diagnosed with an osteosarcoma at the age of 13 and went through approximately 2 years of treatment. I’ve been in remission for almost 2 years. Recently, on December 24th 2019, I was diagnosed again with Myeloid Leukemia SANAR has helped me a lot by giving me and my family psychological support, through the activities we do, the meetings with other young people who suffer from these diseases. We feel supported, we do not feel alone in this fight that is actually not only ours but of many other people like family and close friends, people who are close. Being with other young people makes us feel safer, supported, we support each other especially in times of relapses when the disease appears again. I think SANAR has helped me very much specially in the emotional aspect since emotional help during these diseases is absolutely necessary. It is very necessary to have the best availability for everything, for our treatment, for any surgery, for anything we might need.”

“I am 17 years old. At the age of 12 I was diagnosed with a Non-Hodgkin Lymphoma. I think that all along my illness SANAR has helped me to live, to learn many things and in a certain way to transform the old Genitry into a new Genitry. It has helped me to realize there must be a purpose and a way to be happy and also to help other people with one’s testimony, to serve others. Currently I am a volunteer and I belong to the Group of Adolescents with Cancer of the Foundation and I plan to continue helping for a long time either by visiting other patients who are hospitalized, attending cinema forums and in general, supporting any activities that SANAR wants to do.”

“The fact that SANAR invited Miguel to the trip to San Andrés made us very happy. It had a very special meaning for us because Miguel had never visited the sea and had never been separated from his family for such a long time. His absence during those days confirmed that Miguel is an independent child capable of overcoming adversity and of teaching us that there is always a reason to fight every day, that dreams do come true, no matter the difficulty or disability. Miguel arrived from his trip to the sea of seven colors with other goals to fulfill (such as learning to swim); he had become more independent, more supportive and full of energy to tell all his anecdotes and the names of each of the friends he met.



Today, on behalf of my family I want to once more thank SANAR and its collaborators who made it possible for Miguel to have not only the wonderful experience of visiting the sea, but also of getting to know other great guys that he now considers to be his friends.”

“Thanks to the psychologists of SANAR I was able to accept the disease and understand my diagnosis. When I entered the group of adolescents with cancer, I understood that I was not the only one with this disease and that I had no need to be so arrogant and selfish with my family. I understood that there is life after cancer.”

“SANAR Foundation not only supports children with cancer and their families, it also works inventing strategies for the early detection of child cancer. One of the best strategies I have known is The Tool Box based on AIEPI which makes doctors keep in mind child cancer and thus achieve a timely diagnosis which will give children more opportunities to heal and live. Many thanks to SANAR for being part of the doctors, for helping us to do a better job.”

“I am a Pediatric Oncological Hematologist and I worked closely with SANAR for 10 years. SANAR’s psychosocial support in my professional practice meant making me aware of this disease in children and their families, respecting every life cycle, accompanying each good or bad moment because there is always something to learn and we all have a lot to give and receive. Today I thank each of the spaces I shared and I value each intervention that was carried out.”

OUR VALUES

LOVE: The ability to support with sensitivity and have an affinity for the cause of childhood cancer from a perspective of the redefinition of life and from a development approach.

SERVICE: To serve with responsibility and give a timely and quality answer to all the people related with the Foundation.

COMMITMENT: The ability to take on the cause of children and adolescents with cancer as their own and to commit to offering selfless and permanent professional support throughout the health-disease process

OUR FACILITIES

SANAR is located at Calle 2 No. 14-46 Barrio Eduardo Santos and also Mi Casa SANAR, the first comprehensive support center for children with cancer in the country.

Currently, it has playroom spaces, psychological and social consulting rooms, meeting rooms and administrative spaces.

THE CHALLENGE OF SUSTAINABILITY OF MISSIONARY PROGRAMS IN POST-PANDEMIC TIMES

Traditionally, the resources for the sustainability of the social work come mainly from: the Recycling program, sale of condolence and congratulation bonds, donations from private companies and individuals and fundraising events such as concerts, shows, charity dinners, among others. As a result of the Covid-19 contingency the Foundation's cash flow has been seriously affected, taking into account that one of the Foundation's main financial sources is the Recycling program which had a significant decrease in its income.

As of 2022, with the resumption of face-to-face attendance at universities, schools and churches, it is expected that the recycling collection volumes that have been handled in previous years will be recovered.

Our challenge is to give continuity to the missionary programs of the foundation in such a way that we can respond to the needs of the children and adolescents with cancer that we benefit and that today more than ever require our support.

In order to diversify our sources of income, seeking not to suspend or reduce our support for children with cancer, we have intensified the management of donations with small individual donors through a crowd funding mechanism through the international platform Global Giving, online donations on the page website, the "Rosas

para Sanar” program and the increase in the sale of condolence bonds. Likewise, we have reduced expenses to a minimum and we have taken advantage of all the relief programs offered by the government.

Despite the difficulties, these strategies have allowed us to maintain a fair point of balance in our operations, which is a great achievement, but we need the support of people, companies and non-profit organizations that help us achieve the assurance of our social management and in the future an expansion of the coverage of our missionary programs.

Our challenge is to give continuity to the foundation’s missionary programs in such a way that we can respond to the needs of the boys, girls and adolescents with cancer that we benefit and that today more than ever require our support.

WHO HELPS US

Cepsa Foundation, John Ramirez Foundation, 4-72 Mail Service, Copa Airlines Banco AV Villas, Banco de Bogotá, Fundación Clásico de Ejecutivos El Colombiano, Lito, Efectimedios, Vigía Transportation, Milonga Flowers, Dima Toys, Pilas con el Ambiente Corporation, Wall Street English, Punto Azul Corporation, Difusión, Mercari, BBGS Lawyers, Food Bank, as well as many schools, universities and individuals that make periodic contributions in-kind, services and money.

SYNTHESIS

We have completed 37 years of work in favor of children and adolescents with cancer and we celebrate with pride and hope the impact of Sanar’s work and its contribution to the comprehensive care of childhood cancer and the construction of a public policy that protects life and children’s health in Colombia. We have understood through the experience of these years that, in order to achieve profound and significant changes in the health care system, in terms of quality and ease of access, **as a foundation we must take into account several fronts such as early detection, psychological and social support and occupational therapy for the patient and his family including networking with other entities to influence public policies.**

We have worked with great effort in the construction of missionary programs that promote adherence to treatment and favor survival.

We are working on the development of an information system that will very soon allow us to provide valuable data that gives a more technical account of our work and facilitate the follow-up that we do to each family linked to our missionary programs.

We have developed materials and resources for Early Detection based on the IMCI Guide with the aim of bringing this material closer to physicians and pediatricians and influencing the timing of diagnosis and, consequently, survival.

We continue to invest very important resources in the care of patients and families with very valuable results in terms of coping tools and greater empowerment to assume the disease process.

There are many challenges and dreams that still accompany our path and these will only be a reality if we continue to have the support of our allies, donors and collaborators. Their unconditional trust and support will allow us to continue reaching other regions of the country with our work, and sharing our results with others, the result of committed and quality work from which more than 15,000 families have benefited in our 37 years of life.

We fight to maintain our sustainability and that is why we want to invite you, your family and your company to join us and contribute to our initiatives and projects

OUR WEBSITES

www.sanarcancer.org
www.tapasparasanar.com

SOCIAL MEDIA

<https://www.facebook.com/SanarCancer/>

<https://www.instagram.com/sanarcancer/>

<https://twitter.com/sanarcancer>

<https://www.youtube.com/user/sanarcancer>

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