GREAT AGAINST CANCER

Statistics and stories from Soleterre’s global program against disparities in the cure for childhood cancer

REPORT 2021

SPECIAL EDITION COVID-19
Soleterre is a non-profit foundation that works for the acknowledgement and enforcement of the Health Rights in all of its facets. For this reason, as well as providing cures and medical assistance, it engages in actions to safeguard and promote psycho-physical wellbeing for all, both at the personal and collective level, for all ages and everywhere in the world. To guarantee the inviolable right to health, Soleterre realizes support projects for healthcare facilities and medical staff already at work or, where it is absent, to create healthcare facilities that are adequate to the population’s needs.

Soleterre launched the International Pediatric Oncology “Grande Contro il Cancro” in 2010 with the objective to develop the prevention and diagnosis early on and to decrease the level of pain that the young patients and their families experience. Today the program connects and favours the share of scientific research and clinical practice between 19 sanitary facilities in Italy, Ukraine, the Ivory Coast, Morocco, Burkina-Faso and Uganda.
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On occasion of the International Childhood Cancer Day on February 15 2021, the Soleterre Foundation presents the first edition of the “Great Against Cancer Report 2021” - in continuity with and as an evolution of the Dossier Salute, published for the last five years on this occasion, but in a new format, graphically more flexible and user friendly - with the objective of summing up and presenting the lines of action and the primary impact indicators of the activities conducted over the last year in the countries in which the program is active globally.

2020 has been an especially difficult year for childhood cancer patients in the world, as the Covid-19 emergency has had a multiplier effect on the pre-existing inequalities around access and quality of care. It is precisely because of this delicate historical moment we are experiencing that we can be proud of the incredible achievements reached: **2,865 are the children and parents we have supported** in the daily challenge that is cancer, with an investment of **1,373,000 €** used only for activities and field services, in all parts of the world, to face the growing needs that the Covid-19 emergency has determined for families, both in hospitals and in our shelters.

Specifically, we have acted on two main fronts to address the effects of the Covid-19 emergency: **economic support and psychological support**.

Many parents of children who suffer from cancer have lost their jobs and in addition to this there has been a general increase in

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### 2020

**2,865 CHILDREN AND PARENTS SUPPORTED**

**1,373,000 €** INVESTMENT FOR ACTIVITIES AND FIELD SERVICES

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**Introduction**
Introduction

In order to respond to these needs Soleterre has reinforced its participation for destitute families and those who have been further impoverished by the economic crisis resulting from the pandemic, ensuring economic support for expenses related to cures - medication, diagnostic tests, transportation to hospitals, room and board in cancer centers, COVID-19 testing - to 394 families in Italy and worldwide in 2020, versus the 278 in 2019, recording an +41% increment in the number of assisted families. For them, Soleterre has covered expenses for a value of 209.123 € in 2020, increasing the value reached in 2019 by +46% with 143.090€.

Psychological consequences resulting from this emergency have mounted to the situation, having a significant impact on sick children, particularly in regards to worries for the future and fear of infection, intensifying the pre-existent psychic discomfort. In every context, from Italy to Uganda, passing from Ukraine, Morocco and the Ivory Coast, the 19 Soleterre’s Psychologists have increased their number of working hours guaranteeing 6,224 psychological sessions for children and parents in 2020, against the 4,417 in 2019, registering an increment by +40%.

Today more than ever, on occasion of the International Day Against Infantile Cancer on the 15th of February, Soleterre invites its supporters and friends to unite in sustaining young cancer patients and help them feel less lonely. We can all together wear the golden ribbon - symbolizing the strength of children who are fighting against cancer - and share selfies/stories/posts on our social media profiles utilizing hashtags #soleterre #grandicosi and tag @soleterre_onlus to amplify our message and raise awareness reaching the greatest number of people possible.

To read the stories of the children Soleterre is helping and donate to support the campaign “Grandi Così” it is possible to visit the website www.grandicosi.org.
Soleterre’s international pediatric oncology program “Great Against Cancer” completed 10 years of operation in 2020. The program started from Europe – in Italy and Ukraine. It then extended to Africa. Today, it is operational in Ivory Coast, Uganda, Morocco and is being launched in Burkina Faso. Over the years, an expansion to other countries, like El Salvador and India, is foreseen.

The program is aligned with goals defined in 2018 by the World Health Organization’s “Global Initiative for Childhood Cancer” i.e. to reduce the number of sick children (estimated to be at least 300,000 each year) and to increase the global survival rate to 60% by 2030, thereby reducing social inequality. Indeed, while survival rates in high-income countries have increased significantly (reaching an average of 80%), children in low-income countries are four times more likely to die.

Also, the global target defined by United Nations Agenda on Sustainable Development (and reinforced by World Health Assembly’s 2017 cancer resolution) is to “By 2030, reduce by one third premature mortality from non-communicable diseases..."
The International Program “Great Against Cancer”

through prevention and treatment and promote mental health and well-being” (SDG 3.4).

Soleterre’s program has an integrated approach, which aims to guarantee the right and access to healthcare at every stage of the disease (primary prevention, early diagnosis, treatment and long-term survival) and to provide holistic support to the child and his family, by improving the quality of life through social, physical and psychological well-being.

In these 10 years, the Soleterre’s program has reached 38,715 children and adolescents with cancer along with their respective families, intervened in 19 pediatric onco-hematology departments and health centers around the world, opened 5 family homes, and currently employs over 90 social healthcare workers and educators.
It is hard to explain the situation created in 2020 by the Covid-19 pandemic which upset normally in every area, especially in the healthcare sector. Soleterre has found itself at the forefront of the fight against COVID-19 in every country where it operates, by providing psychological support (48 psychologists and psycho-oncologists employed globally) and supplying personal protective equipment (PPE). Soleterre multiplied its efforts to guarantee continued support to children with cancer and their parents, and extended support to doctors and nurses who remain even more vulnerable and exposed to the effects of the pandemic.

Common and recurring problems were faced in many countries:

- **inability to accept patients for hospitalization** due to transport problems or lack of swabs or serological tests, the costs of which are often borne by families;

- **inconsistent supply of medicines**, medical equipment and supplies to public health services;

- **constant shortage of healthcare professionals in pediatric oncology departments**, aggravated by temporary suspension of some existing personnel considered at risk of contagion;

- **strict quarantine and constant and sudden changes imposed by extraordinary measures**, which increased the vulnerability of families and the consequent exposure to poverty;

- **hospital wards have become high-risk areas**, and consequently inaccessible to external personnel, including volunteers and educational support and relief workers for children and parents.

Soleterre has promoted, at an international level, the coordination of responses for services it provides. Multiple teams of psychologists and socio-educational operators of Soleterre, working in wards and homes across countries, have come together in video-conferences to exchange experiences and adopted solutions, fueling self-training processes on therapeutic treatment methods.

These exchanges have led to the creation of a working group of psychologists, promoted by the International Ethics and Scientific Committee (IESC, see point 4.2). The group met during a global plenary session held on October 20, 2020.
To measure and evaluate the impact of its program, Soleterre has adopted a special Monitoring and Evaluation System, based on the Theory of Change. This system enables Soleterre to have a precise and systematic control over its projects. In recent years, the measurement tools have been progressively refined, to reach a total of 75 performance and result indicators in 2020, applied uniformly in all 5 countries benefiting from the program.

The following sections illustrate the 26 most relevant indicators for analyzing the dual impact created by Soleterre’s interventions: on enhancing medical care and on the overall improvement in quality of life of patients and their family members.

The impact on enhancing medical care is measured by analyzing the combined results obtained in 4 operational areas, directly related to the medical-clinical sphere:

- *rehabilitation and physiotherapy cures* aimed at reducing the neuro-motor effects of treatment.

The impact on improving the quality of life of patients and their family members is measured by analyzing results obtained in 4 operational areas, specifically aimed at increasing the degree of social, mental and emotional well-being of children and their caregivers:

- *accommodation for families* made available near pediatric onco-hematology departments for the duration of treatment;

- *psychological and psycho-oncological support* for sick minors, caregivers and healthcare personnel;

- *economic support for families forced into greater poverty* by bearing direct and indirect costs related to the onco-logical treatment of their children;

- *offering socialization, education and recreation services*, aimed at guaranteeing children and adolescents an opportunity for regular interaction with peers, school continuity, and access to play and entertainment.
The battery of indicators makes it possible to verify the impact of infrastructural support provided by Soleterre to peripheral health centers (for first level diagnosis) and specialized pediatric onco-hematology departments (for specialized treatments). This impact is created through collaboration with public institutes (in particular hospitals and health centres) and civil society organizations (in particular patient and parent associations) in various countries.

A NEW SYSTEM OF FOLLOW-UP IN UGANDA

Soleterre staff who collaborate with St. Mary’s Lacor Hospital have developed new methods for tracking children and families who require constant monitoring and adherence to treatment plan. In fact, by regularly interacting with medical staff of the department,
patients who are scheduled for hospital checks or to continue treatment (according to the Rainbow Family Home records and children’s profile) but do not show up are identified.

For the identified cases, a follow-up procedure is activated: the Medical-Social Assistant and the Psychologist of Soleterre pay particular attention during various activities in the department and in the family home (e.g. psychological support sessions, awareness meetings) to identify cases that, voluntarily or involuntarily, express the need for additional support beyond the period of hospitalization (due to economic difficulties, family hardship, etc.).

Once the list of beneficiaries who need follow-up has been compiled, Soleterre staff contacts the children’s parents by

171,258 euro

MONETARY VALUE OF THE SUPPORT TO CENTERS
telephone to find out if it is necessary to organize a home visit, or if telephone calls are sufficient. For cases that require a home visit, the staff develops an itinerary of visits that optimizes travel to the various communities and villages.

The team is generally composed of an Oncology Nurse, accompanied by a Psychologist or a Medical-Social Assistant. In some cases, where more structured psychological support is needed, both the figures participate in the follow-up mission. The team also establishes contact with the reference medical facility in the family’s residence area to ensure continuity of support.

William Story

William lives in the village of Akwar, in Amuru district, 10 km from the main road, more than 50 km from Gulu. He had symptoms that indicated Burkitt’s Lymphoma. On March 25, 2020, the diagnosis of cancer was confirmed at Lacor Hospital in Gulu. William completed his first-line chemotherapy treatment and was granted a two-week break after second-line chemotherapy. When he returned home, his health began to deteriorate: he developed a severe sepsis infection, so his mother brought him back to the hospital. William received blood transfusions and treatment for sepsis. However, he was unable to complete the treatment due to emergence of some family problems that caused severe discomfort to his mother, who decided to leave the hospital without notice, and returned home with the child.

William life was at risk as he could not complete the treatment. So the Soleterre psychologist, together with the oncology nurse, decided to organize an emergency home visit to his village. The psychologist offered psychosocial support sessions to William’s parents to help them resolve relationship issues they were facing. With their eldest uncle’s support they came up with a solution. Meanwhile the oncology nurse examined the child, finding out that his condition had worsened. Due to acute anaemia, he was weak, had no appetite, could barely stand up, and could not keep his eyes open for long.

The family was also offered food and hygiene supplies to help them as COVID-19 restrictions were imposed on the Ugandan population at that time. As William’s parents were provided support to solve their family problems, the child was able to return to the hospital to complete treatment. Within a few days, his health began to improve allowing him to actively participate in recreational activities organized by Soleterre staff at the Rainbow family home, located inside Lacor Hospital.
Indicators measure the impact of training activities that Soleterre provides in two ways: On one hand, with training and public awareness initiatives aimed at families and minors to facilitate an early diagnosis of the disease, timely access to treatment and better adherence. On the other hand, with events aimed at professional development of healthcare personnel, involved in diagnoses and treatment at various levels.

THE INTERNATIONAL ETHICS AND SCIENTIFIC COMMITTEE IS FOUNDED
10 years of running the “Great Against Cancer” program has created a laboratory and an observatory of best practices related to patients, their families, doctors and nurses, educators and psycho-social workers, associations of family members and volunteers. Across different geographical and cultural latitudes, we have always perceived a common human latitude, especially in emotions experienced by children and adults in dealing with this disease - in their fears, hopes and concrete needs.

This observation provided the motivation to create an International Ethics and Scientific Committee (IESC), on occasion of Soleterre’s 18th anniversary in October 2020. The IESC promotes sharing of knowledge, experiences, treatment methodologies, specialized technical skills (medical and psychological) and intercultural visions, between operators located in distant countries but united by common stories of life and suffering.
We have learned that childhood cancer cannot be defeated by medical treatment alone, but with a combination of medical assistance and psycho-social support for families. For this reason, we believe a therapeutic alliance between doctors and psycho-oncologists is a fundamental part of the treatment.

We wanted to include this dimension in IESC just like it is a part of our day-to-day field work. We invited professionals to sign a common manifesto to share, exchange and build multidisciplinary processes for patients’ treatment, well-being and quality of life.

Currently, 10 primary pediatric oncologists and 10 psychologists and psycho-oncologists from hospitals in 5 different countries adhere to the committee. Among members are two presidents of SIOP Africa (International Society of Pediatric Oncologists) and the president and coordinator of AIEOP Italy (Italian Association of Pediatric Hematologists Oncologists).

IESC’s goal is to develop and sustain a virtual community through the exchange of contacts, experiences and collaborations.
**International Ethics and Scientific Committee (IESC) Manifesto**

**Considering that**

Non-communicable diseases, including cancer, contribute to **more than two-thirds of deaths worldwide today**, accounting for **7 in 10 deaths**, and four-fifths of these deaths occur in Low and Middle Income Countries (LMICs).

**Every year at least 300,000 children** under the age of 15 are estimated to be diagnosed with cancer worldwide, **survival rates** are much lower in LMIC countries where children are four times more likely to die.

**Referring to**

The **United Nations Sustainable Development Goal No. 3.4**, which aims at reducing by 2030, the premature mortality from non-communicable diseases by one third, through prevention and treatment and promote mental health and well-being.

The **WHO Global Initiative for Childhood Cancer**, which aims at reaching at least 60% survival for children with cancer by 2030, thereby saving an additional one million lives and doubling the global cure rate for children with cancer.

**Soleterre Foundation** is promoting the creation of a network of medical institutions and professionals with whom it collaborates for the **International Program “Great Against Cancer” (GAC)**. This network will be called the **International Ethics and Scientific Committee (IESC)**, and will aim at addressing the following global challenges related to pediatric oncology:

- **Knowledge sharing:**
  share training and medical advancements between high income countries and LMICs, adapting clinical practices to the scientific-technological conditions and opportunities in different countries;

- **Consistent quality of treatment:**
  provide appropriate diagnostic and surgical equipment, medical devices, drugs for every sick child;

- **Dignity in care:**
  enable children and their families to face the disease in a dignified manner, promote and protect their rights, guarantee adequate social, psychological, logistical and educational support services.

The IESC will take the form of a permanent virtual community, aimed at **facilitating the exchange of skills and experiences of individual members, to promote multi-disciplinary cooperation on an international scale**. Signatories of the IESC Manifesto undertake to network with other members of the committee and **share their scientific and technical competence**.

The IESC operates in the context defined by SIOP “to improve understanding of the impact of childhood cancer on the patients’ well-being as well as on that of their family members, within a developmental perspective. It is important to make psycho-oncology an active component of cancer treatment, counseling and rehabilitation. The pediatric psychosocial clinicians have become vital members of multidisciplinary clinical and research teams, adding specialist knowledge to treatment and research of children with chronic or life threatening diseases.”

Membership is by invitation of the Soleterre Foundation, and is extended to medical institutions and professionals in the health-care, scientific and psycho-social field who are existing partners of the organization.
The indicator quantifies investment made by Soleterre in innovative medical research projects aimed at identifying and developing new therapies in the fight against childhood cancer.

“READY BY YOUR SIDE” 
NEW FRONTIERS IN CARE

Medical research, especially in the pediatric oncology field, is very limited, as it is a rare disease and therefore of little pharmaceutical interest. Since 2012, Soleterre has been collaborating with the Pediatric Oncology Department of San Matteo Polyclinic in Pavia. It is one of the main centers in Italy for diagnosis and treatment of leukemia, lymphomas and solid tumors of the child, specializing in stem cell transplants.

Patients who receive a stem cell transplant are exposed to a prolonged period of impaired immune system function. Thus, administration of anti-virus drugs is a part of the therapeutic protocol to prevent infections that can seriously endanger the patient’s life. However, for many viruses there are no truly effective drugs and those currently available may be toxic or ineffective.

In recent years, research has developed a new category of drugs called cellular drugs, which consist of lymphocytes trained in the laboratory to recognize and attack virus-infected cells or cancer cells. Cellular drugs are not a substitute for traditional therapies such as chemotherapy and radiotherapy, but are complementary to them.

Thanks to a high degree of innovation they are much less toxic because they only affect the diseased cells.

Since mid-2020, thanks to contribution from the Just Foundation, Soleterre has launched a very important research project with the Cell Factory of Policlinico San Matteo in Pavia, specifically to develop and produce these cellular drugs starting from the patient’s or donor’s cells. The project is creating a Bank of Cellular Cancer Drugs ready for use and available in a short time to meet urgent requests from stem cell and organ transplant centers. In second half of 2020, the first 4 batches of the multivirus-specific drug MVST, were tested, found to be usable and made available for clinical use. Currently, 60 units of MVST doses have been produced.
The indicator measures the impact of physiotherapy services provided by Soleterre, through which benefited minors can (totally or partially) recover their neuro-motor skills compromised by medical treatments.

**PHYSIOTHERAPY IN DACHA**

In the Ukrainian health system, physical rehabilitation of children with cancer was not planned. The well-being of patients during and after treatment was not considered a priority. In reality, however, many children undergoing cancer treatment are at risk of induced disabilities, particularly at the neuro-motor level, and need physio-therapeutic rehabilitation to recover impaired functions.

In 2009, Soleterre and Zaporuka introduced a rehabilitation service in Ukraine for the first time, in the pediatric ward of National Institute of Cancer. Two physiotherapists were hired and a rehabilitation room with new devices was set up.

Most patients in rehabilitation have undergone surgery to remove bone tumor of upper or lower limbs (osteosarcoma, Ewing’s sarcoma etc.) and have had an endoprosthesis (bone prosthesis) or a donor bone installed. Unfortunately, situations in which children have to be subjected to limb amputation are not uncommon. Rehabilitation especially helps these cases to accept their new physical condition and
prepare to live with the prosthesis. Patients with other oncological diagnoses also need rehabilitation, to recover muscle tone lost during the long illness.

In 11 years of service, more than 500 children with cancer have benefited from the rehabilitation services offered by Soleterre together with Zaporuka.

Physiotherapist Tetiana Makovska says “During all these years of working with children, I am convinced once again of how strong, wise and patient they are, more than we adults believe. They are heroes and I feel proud of all of them”.

During this particular year, marked by the Covid-19 pandemic, physiotherapists have also learned to work online: on one hand this made it more difficult to monitor the patient’s progress, but on the other hand it allowed them to continue rehabilitation at a distance, despite the isolation.

Way to go, dad!

Rehabilitation is a rewarding service because results are visible quickly: from seeing a child lying almost motionless on the bed, to him walking by himself within a few days.

This is the story of R., a 14-year-old boy who was being treated for osteosarcoma. Removal of a part of the iliac bone affected by tumor forced him to stay in bed for several months before being able to begin rehabilitation.

Only after a few months R. received permission from the doctors to try and stand up, first with a verticalizer, then with crutches. It is always a delicate passage, a moment of great pain, in which motivation plays a very important role. For R., the real motivator was his dad, who supported him during each session and found the right words in most difficult moments.

Over time the boy started using devices like Motomed, doing exercises on the Swedish ladder, with gradually increasing weights, making him stronger every month and allowing him to walk without crutches.

Last summer R. was discharged from the ward and returned home, staying in online contact with physiotherapists during Covid-19 pandemic. His gait has become more and more fluid and confident with each passing day.

The treatment
Rehabilitation
The battery of indicators measure the capacity of family homes, created by Soleterre, to host families with sick children during treatment.

Family Homes are located near main pediatric onco-hematology wards, so as to offer guests the opportunity to receive outpatient treatment in the hospital and be supported in a family environment outside the ward. In this way, patients are guaranteed an emotionally adequate and protected environment and hospital wards have a lighter workload.

AKWABA MEANS WELCOME!
The first “AKWABA family home” in Ivory Coast, (Akwaba means “Welcome” in the local language), opened its doors in 2014. Since then, a lot has happened. The home has held over 400 children and their families in maternal embrace.

Newly diagnosed patients with the most elevated economic risk are referred to Soleterre’s family home by doctors from the University Hospital of Treichville (Abidjan) and the “Mere et Enfant” Clinic (starting 2020). These two hospitals have the only 4 pediatric oncologists present in the whole country.

Majority of specialized doctors emigrate abroad, where medicines are not in short supply and there is a more solid public healthcare system.
Akwaba has moved three times since 2014, to improve reception facilities for families. One of the unwelcome surprises of COVID-19, has been a short supply of some very urgent chemotherapy drugs that Soleterre is helping to procure. But 2020 also brought a positive surprise: the availability of a **bigger and more beautiful house**, which was put on rent by owners at a discounted price.

The new house has an external courtyard with slides and swings, another large internal courtyard, three verandas to enjoy cool outdoors (a real breath of fresh air for guests, given the average temperatures) and 5 organized and modern common rooms. There is also a room for education and entertainment, with a wonderful mural full of colors of hope painted by a local association, and a closet full of games, which gets continuously emptied and filled up.

**In Akwaba up to 12 families can be accommodated at a time.**
Usually it’s the patient and a parent, but sometimes siblings are added, because the parent has no place to leave other children and there is a risk of abandoning treatment. In Ivory Coast, many parents still abandon their children’s treatment due to economic difficulties: but the numbers are a little lower, thanks to the home. Early intervention is an important factor in curing pediatric cancer, much more than it is in treating cancer in adults. Akwaba family home is providing this opportunity of early intervention to children and their families.

Aware of how much difference a family home can make, Soleterre will open another AKWABA Home in Ouagadougou, the capital of Burkina Faso. The result of a collaboration with GFAOP (Franco-African Pediatric Oncology Group) which already supports the activity in Ivory Coast, the new home will initially welcome about 10 families.

G is eight years old, the seventh among 10 kids and lives in Bangolo, Ivory Coast. It all started for him in September 2020 with dental pain. His father bought him pain medication but the pain returned in two weeks, accompanied by inflammation in the gums. His father returned to the pharmacy and repeated the treatment, but a week later, the abscess exploded in the child’s mouth. This time his father went to the health center in Bangolo where treatment was prescribed but despite the therapy, G’s cheek continued to swell more every day.

They returned to the doctor who detected a tumor, Burkitt’s lymphoma, and referred them to Treichville University Hospital in Abidjan. With no savings to pay for travel and medical care, G’s father mortgaged his cocoa plantation for a sum of 150,000 CFA francs (around 220 euros). With this money they reached the pediatric oncology unit of CHU de Treichville in late November.

At the hospital, the initial evaluation was carried out and G received two chemotherapy treatments. Soleterre’s Casa Akwaba offered G and his father free accomodation and social, economic and educational support for the duration of treatment. Back in Bangolo, with Soleterre’s support, the primary education inspector, teachers and students raised a contribution of 150,000 francs at the community level to support the family.

As an African proverb goes: “It takes a village to raise a child”.

The home will be opened in 2021, once administrative formalities are completed. Agreements with hospitals are being signed and local staff of the home are being selected which is a fundamental component.

No one has a marginal role in Soleterre’s family home, not the driver who accompanies the children to the hospital for chemotherapy making them sing and smile, nor the guardian who opens the door to welcome families frightened by the diagnosis. Wish us good luck and we will say “AKWABA”!
An important intervention by Soleterre is the psycho-oncological support provided to patients and caregivers to help them deal with the trauma and challenges posed by the disease.

The impact of psycho-oncological support is measured by a battery of indicators that cover both the number of beneficiaries and the extent of counseling services provided.

THE PSYCHOLOGICAL SUPPORT SERVICES IN POLICLINICO SAN MATTEO, PAVIA
A team of seven Soleterre’s psychologists work in the pediatric onco-hematology department of Policlinico San Matteo in Pavia. They take care of the emotional, psychological and relational well-being of patients and their families.

The ward can accommodate sixteen in-patients and the transplant area has a capacity of five.
Children are treated for haematological malignancies (lymphomas and leukemias), some tumors and haematological diseases (anemia).

When the Covid-19 pandemic was at its peak, work had been carried out remotely to provide continued support and a safe space for discussion to families. When the team was able to resume their work in the ward and day-hospital, it was much welcomed by the children.
The Covid-19 emergency had put the children in a condition similar to their peers - with respect to online school, restricted everyday life and the use of masks.

Their disease and treatment still differentiated them, but they felt similar to others which made it easier for them to endure the suffering. The isolation was also advantageous in protecting them from infections when their immunity was low following the treatment.

On the other hand, hospital stay became more complex because visits from family members and volunteers were prohibited. Over time, this limitation became more and more problematic because it made parents feel lonely in dealing with the disease and with life in the ward.

Going through the pandemic emergency together, provided an impetus for parents and children to exchange their experiences. Sharing experiences and storytelling has a dual functionality: families who share their stories have the opportunity to tell, listen to each other, re-phrase and give a deeper meaning to what they have been through.

Families who hear the stories of those who are facing or have already faced the disease and treatment, not only feel less alone, but are also able to acquire ideas that become a resource for them.
Talking about oneself through Narrative Medicine

“L was a seemingly healthy child, just felt a little more tired than usual. He had his blood tests done one morning in January, in the afternoon we found ourselves back in the ward for further tests on some “strange” cells. Diagnosis was in less than 24 hours. Fear is the first feeling you experience and it never leaves you, waiting becomes your companion in the period that follows.

And above all, you begin to ask yourself questions, many questions, but soon you understand that there are no answers.

Acceptance is the most important thing but also difficult to do, but from that point onwards, it gives you the strength required to take every small step. It is essential to go through this journey one day at a time, without big expectations, to be happy with a little progress and continue to be positive even in the darkest moments.

Surely the environment that surrounded us (the hospital) and the wonderful people we met were of fundamental support. We found doctors and nurses who made L feel protected and helped him a lot, reassuring him in moments of sadness. The initial period was not easy, especially because L felt well and could not understand why he would have to stay in hospital for a long time.

Despite this, he never lost his sense of joy and desire to play, laugh and plan for the future. This, I believe, was his greatest weapon to fight this important battle.

Today treatments and hospitalizations are a part of our lives, but we go on day after day and try to enjoy even small moments of normal life, whenever possible. The experience of dealing with the Covid-19 emergency, on one hand was difficult because of fear of infection, on the other hand, seeing his peers locked at home and without external contact, exactly like him, has certainly helped L to feel less sick.”
The indicator shows the value of personalized economic support provided to patients facing extraordinary or particularly critical conditions of poverty or family hardship, which jeopardize the very possibility of accessing treatment.

In the population supported by Soleterre, the disease often affects families that are already economically challenged and find it hard to bear the additional costs, both direct (for transport, food and accommodation away from home, health insurance, health migration, etc.) and indirect (loss of employment due to the need to provide care to a sick family member).

MIGRATION TO ACCESS HEALTHCARE AND FINANCIAL TOXICITY OF CANCER

Censis has calculated that in Italy about 750,000 people have to travel to access better healthcare every year, of which about a quarter travel over 400 kms. This is the most dramatic type of migration caused due to the absence of specialized hospitals in one’s own territory, or due to the presence of long waiting lists which prevent full access to the Right to health.

Migration to access healthcare is particularly high for pediatric cancer: about 80% of cancer patients move from the South to the Central-North region of our country. This brings a very high level of complexity and social costs. It is important to note that many cancer patients forced to seek treatment far from their place of residence are minors - hospitalizations outside the region exceed 70,000 per year. Apulia, in particular, is one such region with the highest number of people migrating to other regions to access better healthcare, resulting in about 40,000 hospitalizations every year.

Since 2019, thanks to an association with SIMBA ONLUS, the Great Against Cancer project has also reached the city of Taranto, Apulia - in the pediatric oncohematology department.
of Santissima Annunziata Hospital. The goal of the project is to ensure a high-level of psycho-social care and support, increase citizens’ trust in the hospital, and reduce healthcare related migration from the region. The pediatric oncohematology department of the hospital welcomes about 80 patients every year, suffering from leukemia, lymphoma, soft tissue sarcomas, brain tumors, acquired and congenital anemias, and platelet disorders.

Thanks to the tireless work of head physician Dr. Valerio Cecinati, the department has become a recognized cancer treatment provider. Not just in the city of Taranto or the region of Apulia but also in neighboring regions such as Calabria, Basilicata and Abruzzo.

Starting from March 2019, Soleterre has decided to provide an immediate response to the problem of oncological poverty, providing financial support to some families of pediatric cancer patients in Taranto. Especially to those families who are forced to travel to bigger hospitals in the Central North region. Soleterre’s commitment is to provide an integrated care solution to these families, not just financial support. Psycho-oncologist Maria Montanaro works to identify the needs of families and find solutions that can be offered locally.

Among the beneficiaries of the project is little Carlo, who is eight years old and lives in Terlizzi (in the province of Bari) with his mother, father and little sister Francesca, one year younger to him. In 2014, Carlo was diagnosed in Milan with a rare form of hepatitis with haemolytic anemia, which caused major skin problems, among other effects. After the first transplant in 2015, Carlo has had two serious relapses, in 2017 and 2019. Due to the failure of the transplant, little Carlo is currently undergoing a new experimental treatment, and thus, has to remain under constant medical supervision. He is lucky not to require hospitalization but he has to go for regular check-ups and infusions at the Day Hospital.

Opening of the pediatric oncohematology department in Taranto gave Carlo and his family the opportunity to be treated close home, and to limit travel to Milan to once a month. Despite this, however, the travels weigh heavily on the precarious finances of the family, with his father being the sole earning member and being able to work only occasionally.

Soleterre began to support Carlo by covering the expenses of these monthly trips, which initially took place by train. Since the Covid-19 pandemic broke out, it has no longer been possible to travel by train due to risk of infection as Carlo’s immune system is severely weakened by the treatment. Soleterre supported the family and arranged for a safe means of travel by car.

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The indicator measures the activities of socialization, education and recreation, organized by Soleterre with the active contribution of volunteers. These activities provide relational and educational benefits to sick children and adolescents (through study, play, art) and provide support to their parents. For both children and their caregivers, these activities represent precious opportunities to rediscover moments of serenity and courage, and help to overcome fear and loneliness during long periods of hospitalization and treatment.

**WE STUDY AND PLAY AT THE “RAINBOW HOME” (UGANDA)**

Rainbow Home, at St. Mary’s Lacor Hospital in Gulu, Northern Uganda, hosts children undergoing treatment at the hospital and their parents. The Soleterre staff that manages the house has organized educational and recreational services for the children. Now the children can participate in educational activities even while being away from school, and recreational activities allow them to face the period of hospitalization with greater serenity. Soleterre provides children with the necessary teaching materials to study, draw and color, and games that can be played individually or in groups. Recently, a room in the hospital was converted into a cinema room to accommodate up to 20 young spectators. Both recreational (animations) and educational (documentaries) age-suitable videos are played every day.
Some recreational activities are also directed at parents, to keep them occupied and keep their minds clear of negative thoughts.

The main activity is that of farm therapy: since many of the parents come from a community of agriculturists, this activity is familiar to them and mimics their normal daily life. A kitchen garden with the necessary tools has been set up near Rainbow Home. Seasonal gardening activities are carried out here, usually involving 3 to 8 parents at a time, with the technical support of an agronomist.

Another activity Soleterre offers is to buy and make available musical instruments for parents who know how to play. This has a positive impact on those who play and also on other guests who listen - both children and adults. The future plan is to organize lessons for children and parents who do not know how to play a musical instrument yet.

Omara and music therapy

Omara is 37, from the western village of Dec in Katum Sub County, Lamwoo District. He is currently taking care of his 10 year old daughter who has been diagnosed with kidney cancer. His daughter’s illness has caused a lot of psychological distress to Omara and his family.

With Soleterre’s support, Omara benefited immensely from music therapy while staying at Rainbow Home. He likes to play local musical instruments as he it helps him to cope with stress while taking care of his daughter. He has also taught other visiting parents to play local musical instruments and this has provided a source of entertainment for other children and their caregivers. This has greatly helped parents at Rainbow Home to cope with their emotional distress, creating pleasant memories and distracting their minds, especially when the music they love is played using local techniques.

One day Omara confided in us: “This music therapy has helped me a lot to socialize with other parents and every time I play these instruments I forget my problems and I relax completely. I thank Soleterre and I hope that there will always be someone at Rainbow Home who teaches guests to play these instruments, it is a source of entertainment for children and also for adults.”
Much progress has been made in these first 10 years, but the path ahead is still long and arduous, studded with old and new difficulties (as the pandemic is teaching us). Common goals of containing and reducing childhood cancer, promoted by global initiatives of the United Nations and the World Health Organization, however, provide courage and hope of combining and redoubling efforts.

The direction taken by Soleterre over the years to promote and encourage global partnerships among different countries and entities (public and private, doctors and psychologists, hospitals and parents’ associations), was strengthened in 2020 with the establishment of the International Ethics and Scientific Committee. Soleterre’s goal is to consolidate and further develop this synergy among international networks committed to a similar purpose, promoted by international or civil society organizations.

Today, more than ever, it is necessary to combine forces, create a system, exchange skills and best-practices (on a thematic and geographic level) in order to reach our common goals as quickly as possible and create an impact globally. With a special focus on the African continent.

At the national level in Italy, Soleterre has seen evidence of the importance of psychological support in treating pediatric cancer and also of the unfortunate lack of resources provided by the national health service. Hence, Soleterre’s commitment is to strengthen efforts at two levels. At one level, to expand psycho-oncological services nationally, making resources and support available, especially in territories that are most lacking. We started from Taranto and the future intent is to replicate a similar service in new territories, especially in South of Italy. At the second level, to call attention of institutions (at various levels) to their public responsibility and commitment of protecting the rights and guaranteeing conditions of equity and well-being to sick children and their families.

Finally, a third level of commitment is to the field of research, as stated in the IESC Manifesto regarding equity in knowledge. There are already many initiatives in the pipeline in different areas, from medical research (in Europe and Africa) to psycho-oncological research. A particularly innovative and challenging area is that of environmental research: to better understand the correlations between pollution and environmental contamination and their impact on public health, specifically on risk of pediatric cancer. From our observations in Italy and globally, we have often suspected correlations, in cases like Chernobyl and Taranto. Italy has undertaken excellent initiatives on this path at an global level, but much remains to be done.

The challenges are, therefore, many and complex. Our hope is to be able to tackle them by combining forces, with tenacity, and to make a meaningful contribution in achieving international goals.
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GREAT AGAINST CANCER

Statistics and stories from Soleterre’s global program against disparities in the cure for childhood cancer

REPORT 2021

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