

100% committed to cure: Personalized medicine and advancing research towards the goal of finding a cure for paediatric cancer

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The Brazilian branch of INCTR coordinates programmes in Latin America, particularly in paediatric oncology and palliative care. The branch has a major role in training and education in clinical trials management, and is currently developing a clinical, pathological and radiological review for Brazilian patients with brain tumours in partnership with SOBOPE Brazilian Society of Paediatric Oncology; as well as in promoting the development of healthcare professionals involved in the psychological and multidisciplinary support of cancer patients.

As associated institutions INCTR, Brazil, TUCCA - Association for Children and Adolescents with Cancer - and the Department of Paediatric Oncology at Santa Marcelina Hospital, put into practice INCTR's international directives, being a worldwide benchmark for paediatric cancer treatment, clinical research and palliative care.

Our ultimate goal is to achieve a 100% cancer cure. To this end, we have developed a Centre of Excellence for the Care of Children and Adolescents with Cancer in partnership with Santa Marcelina Hospital, aligned with INCTR's main global objectives.

The major achievements made at this Centre of Excellence

include the establishment of a state-of-the-art inpatient ward and outpatient department for children and adolescents with cancer at the Santa Marcelina Hospital that serves a population of some four million people in one of the poorer areas of São Paulo.

As a result of the research and personalized care offered by TUCCA, Santa Marcelina Hospital and INCTR Brazil, more than 70% of children and adolescents with cancer treated at our centre can now be cured. Unfortunately, this excellent result is not achieved in most centres in Brazil. But, while the results are similar to those obtained in North America and Europe, there remain some patients whose tumours are resistant to treatment. Care, however, is never withheld from children even when cure is not possible, and the very existence of a hospice - the first paediatric one in Brazil - reminds us that each of us has the right to die without physical pain and with dignity.

It provides comprehensive end-of-life care that is not limited to the required medical and nursing care, but also includes psychosocial support. Assistance is provided after death - which includes not only support, but also to ensure family wishes are respected when life ends.

The hospice is supported by funds raised by TUCCA and



donations from the business community. In spite of the poverty of the families who have lost a child, they too contribute in small ways to show their appreciation for the care they received at the hospice.

The branch has also a major role in the treatment of retinoblastoma. Sadly, retinoblastoma is commonly diagnosed at a late stage in countries with limited resources. Efforts aimed at early detection can reduce the stage at diagnosis, potentially improving cure, saving the eye (preserving vision) and enabling simpler and more cost-effective treatment.

Considering this challenging context, we have developed an international early diagnosis campaign translated to over twenty idioms, including African languages. More recently, we have succeeded in having 18 September declared as the “National Day of Awareness and Encouraging Early Diagnosis of Retinoblastoma”. To gain the attention of the Brazilian population of the importance of the need for early diagnosis of retinoblastoma, TUCCA and INCTR Brazil managed to send this message to the general public with the cooperation of many others. One of the most notable activities took place at night, when the lights that illuminate the monument of Christ the Redeemer, which stands some 124 feet high atop the Corcovado hill in Rio de Janeiro, were switched off for several minutes to draw attention to the blindness caused by retinoblastoma.

We also maintain an Integrated Retinoblastoma Care Centre in partnership with Santa Marcelina Hospital. It offers advanced therapeutic options, such as intraarterial chemotherapy. In most cases, the technique has allowed preservation of a child’s eye and vision, resulting in 70% of eyes being preserved.

Aligned with our mission, psychosocial support is provided in several ways:

- Psychosocial support and counselling are provided to



patients and their families at the time of diagnosis and continuing throughout the treatment.

- A lodging-house has been built for the parents and patients who live far away, where distance makes it difficult for them to go home in-between treatments.
- Daily transportation is provided for those who live locally, but who have difficulty accessing public transportation – either due to disability or who live long distances from points of access to public transportation.
- Transportation is also provided for patients who live in the cities outside Sao Paulo where cancer care is not available.
- Schooling is provided to children to ensure that they continue their education during treatment in classrooms at Santa Marcelina Hospital.
- A special kitchen where a locally famous chef teaches parents how to cook has been set up. This weekly session brings families together in a more relaxed atmosphere.

We are currently focusing on three major initiatives: a multi-institutional collaborative study on childhood leukemia, in partnership with the National Institute of Cancer (INCA), the development of a biobank aimed to have a double impact by providing country-specific access to personalized medicine and advanced research and a molecular pathology laboratory. Since its inception, the laboratory has been developing and performing state-of-the-art molecular-based tests to aid in the diagnosis and management of Medulloblastoma. All initiatives are highly cost-effective from a societal perspective and benefit patients with brain tumours, leukemia and retinoblastoma throughout the country, even those not treated at our centre.

Our vision for the future is to be able to ensure access to appropriate treatment and supportive care for children and adolescents with cancer, from all over the country, even those who are not yet diagnosed. We are 100% committed to cure. ■

