

Improving the Quality of Childhood Cancer Care in Northern Uganda

About INCTR

The International Network for Cancer Treatment and Research (INCTR) is an international not-for-profit organization based in Brussels, Belgium. INCTR is dedicated to helping to build capacity for cancer control by increasing the ability of local partners in low- and middle-income countries (LMIC) to diagnose and treat cancer promptly, with the ultimate goal of increasing survival rates and quality of life of all cancer patients. One of INCTR's major programs is the management of childhood cancer in LMIC.

Background Information

As of 2014, Uganda had a population of 39 million that was predominantly comprised of children and adolescents (48% were less than 15 years of age). Approximately 35% of the population live on less than \$1.90 a day and 84% of the Ugandan population live in rural regions. With respect to health care, 78% of expenditure is out-of-pocket and 26% of expenditure comes from outside the country. In short, there is little government expenditure on health care per person (\$47) in Uganda.

St Mary's Hospital Lacor (LH) Gulu is located in northern Uganda and is the second largest hospital in the country. It is a private, not-for-profit hospital and receives only a small fraction of its funding from the government. LH serves a population of over 4 million people and more than half of them are children. Children suspected of having cancer are likely to be referred or come directly to LH for evaluation and treatment, assuming that they have a means of transportation. Children may also come from other large districts within the northern part of the country to receive treatment for cancer. Many families of children with cancer must travel long distances and therefore, exhaust all of their financial resources, in order to reach LH.

INCTR's Partnership with St Mary's Hospital Lacor

Since 2010, INCTR has worked with St Mary's Hospital Lacor (LH) to improve the care and outcomes of children with Burkitt lymphoma (BL), which is one of the most common childhood cancers – accounting for more than 50% of all pediatric cancer in equatorial Africa. BL is one of the few cancers that can be cured with chemotherapy alone. INCTR along with its partners in sub-Saharan Africa designed a standard treatment protocol for BL. It consists of a first-line (FL) regimen for newly diagnosed patients, but includes a second-line (SL) regimen for those who fail to respond to FL or who relapse early following completion of FL. The protocol, otherwise known as INCTR 03-06, was implemented in 2004 and to date over 800 patients have been treated with an overall survival rate of 62% at 5 years. LH began enrolling patients on the protocol in early 2010 and since then, they have treated nearly 250 patients with BL. In an analysis of the first 118 patients treated according to the protocol, the overall survival for children with BL was 71% at 3 years, an excellent result for Africa, particularly since the majority of their patients presented with very extensive disease. The preliminary results were presented at the International Conference on Malignant Lymphomas in Lugano, Switzerland in June 2015. Because of the strict follow-up procedures that had been put into place, most children with BL completed planned treatment and if they did not, they were followed up at home to ensure that the outcome data was accurately represented. The LH results showed what could

be achieved for children with BL through the use of a uniform treatment protocol using a feasible, but effective treatment approach.

Present Collaboration

In 2016, the departure of key personnel led to major deficiencies in diagnostic and clinical services for children with BL and other childhood cancers. INCTR and LH mutually agreed to re-establish LH's capacity to treat BL and to develop and implement other uniform standards of care for other common childhood cancers diagnosed and treated by LH (such as Wilms tumor and rhabdomyosarcoma). In order to accomplish this goal, more and better trained staff, high quality diagnosis, standard treatment protocols for the management of pediatric cancers and treatment-related complications will be needed. The design and development of simple data collection tools that capture patient presentation features and outcomes in order to document results achieved will also be needed. It will be necessary to re-start public and professional awareness campaigns about the signs and symptoms of childhood cancer in order to ensure earlier referrals to LH with children within the region who are suspected of having cancer, and to develop the ability to raise funds locally.

There is now a family home for children and their parents who do not require in-patient treatment that is located on LH's campus. INCTR through LH has developed a relationship with key personnel involved with the family home. This relationship was necessary in order to more fully understand the services available to children and their families and to learn about services that still need to be addressed. Although the family home provides many different services to patients and their families, these services are usually only available to out-patients, leaving many needs of children and their parents who are in-patients unmet. The family home's existing resources are insufficient to provide services to more patients and families. Nor are they sufficient to expand services that INCTR, LH and the family home recognize are required in order to provide expanded psychosocial support for families, more home visits for patient follow up, and to more frequently hold public awareness campaigns in villages. As a result of site-visit in 2017, INCTR, along with LH and the staff at the family home, recognized the need for a teacher for the younger children – who are falling behind in their education due to prolonged absences from school due to treatment. A teacher was appointed and INCTR provides salary support. This teacher is not able to provide education to all of the children, particularly older children. More frequent public awareness activities throughout the region are needed. These can be accomplished not only by going to the villages and health centers to educate the public about signs and symptoms of childhood cancer, but also through regular public service announcements. Therefore, it is important to augment funds for the family home to enable their staff to do more. This will also allow the LH staff to have more time to participate in training sessions and to focus on improving clinical care for the children.

INCTR and its branch in Brazil will work together with the staff at LH and the family home to provide training and education to all personnel involved in the care or support of children and their families to improve the quality of the services that the children seen at LH receive. A series of both on-site and on-line training sessions are envisioned to assist all involved in the care of children with cancer to achieve this goal. The training tools can be re-used in other childhood cancer units across Africa.

Long-term Impact

Through this project, at least 200 children can benefit from having access to treatment – the average cost of treatment for children with the more commonly seen cancers at LH is approximately \$250, including medications to manage side-effects of treatment. The majority of costs associated with treatment that are normally incurred by families who are struggling financially can also be covered. If

more professional and public awareness campaigns are conducted, this may increase the number of children presenting or referred to LH with early stages of disease such that they have the best opportunity for cure. INCTR through its Brazilian branch can lend its considerable expertise in assisting local personnel – both at LH and at the family home - to create culturally relevant programs to develop locally sustainable funds for children with cancer seen at LH. Collecting basic data about the diagnosis, presentation features, treatment and outcomes on all children with cancer seen at LH is essential to demonstrate the success of the project. Through success, the project can serve as a model of care for the treatment and management of children with cancer in other districts in northern Uganda.

How Your Support Can Help

Your support can make a difference to a child with cancer in northern Uganda. It will be used to cover the costs of chemotherapy and other medication. It can ensure that parents struggling to provide food for their children and themselves do not go hungry and that they have a place to stay during treatment. It can provide the necessary transportation costs to and from the LH such that they have access to and receive the specialized care that they need. And, it can be used to train health care personnel in the care of these children and raise public awareness to minimize delays in reaching LH.



Children with Cancer at St Mary's Hospital Lacor Need Your Support



Building capacity for cancer treatment and research in developing countries

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