Dear friends,

Greetings from the Palliative Care Association of Uganda (PCAU).

Thank you for your continued support to work of supporting children heading families as well as children facing cancer to receive treatment.



In this update, we will focus on how we have we have supported 27 children and their families to thrive the distress and suffering that comes with battling cancer.

Some of you will remember that the Palliative Care Association of Uganda (PCAU) was compelled to initiate this project and realized that many children who are diagnosed with cancer abandon treatment. Statistics by the Uganda Cancer Institute (UCI) show that 30% of the children who are diagnosed with Cancer abandon treatment in Uganda. The UCI receives an average of 700 children with cancer each year, and their survival rate is at 50 percent, which is below the 80 percent survival rate in developed countries.

A study by Oncologists in Southwestern Uganda further compelled the PCAU to pilot this project in the same region. In a qualitative study, carried out in October and November 2020, in-depth interviews were conducted with caregivers of children who had abandoned cancer treatment at the Pediatric Cancer Unit of Mbarara Regional Referral Hospital in southwestern Uganda.

The study established that Money was the Problem": Financial Difficulty is the Main Reason for Treatment Abandonment by Children with Cancer in Southwest Uganda.

Read more about the research here https://pubmed.ncbi.nlm.nih.gov/34459106/

In the last three months, PCAU and partner Kitagata Hospital supported a total of 27 children diagnosed with cancer to continue treatment. This was possible because of the funds that you give to PCAU. When PCAU initiated support for the Palliative Care Unit at Kitagata Hospital in July 2018, the Unit was supporting only 4 children who were living with cancer. So far the unit has 27 active children living with cancer and other life-limiting illnesses such as sickle cell disease (5) children, heart disease (3), and renal diseases (4) children. These medically fragile children always require constant social care.

The children with cancer are presenting with Leukemias, Lymphomas, Neuroblastoma, Kidney tumors, and Malignant bone tumors.

The biggest support we offer is transport to caregivers to ensure that children do not miss their appointment days at the hospitals.

The support to the Palliative Care Unit at Kitagata Hospital has come with some achievements:

- The children have continuously received care and have all adhered to treatment.
- The quality of life of the children and their families has greatly improved
- The palliative care unit at Kitagata hospital has been functional and accredited for students to gain experience

We still need to do more such as:

- Offering more funds to afford to feed the children and their caregivers during their hospital visiting days.
- Supporting the palliative care nurse and the social worker to conduct home visits,

Holistic Care for children continues in Uganda despite Covid



especially for psychosocial support and counselling. Some of the family members (especially men) are disinterested in the care of the children which distresses the immediate caregivers.

 More funding support to offer medical sundries and supportive devices such as cotton, goose, walking crutches, and wheelchairs.

Read a detailed story about this project published on ehospice https://ehospice.com/africa_posts/ holistic-care-for-children-continues-in-uganda-despite-covid/

The Palliative Care Unit has not been able to sustain the Psychosocial Day which was such a successful activity. There is a need to focus on this one: Bring children and their caregivers together to unite with each other after every 3 months. This will enable them to cope through sharing stories, sharing a meal, watching television, playing, and praying with each other. This peer support is important in the process of healing for the children.

During the previous Christmas Seasons, we offered the families some charismas packages. We hope we will be able to do this too. Whenever we receive any amount, we shall offer the children and their families some charismas package. This will be so meaningful to them. We hope we will be able to that with your support!

Once again, thank you so much for your support. Will be grateful to hear from you.

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