

PCAU PARTNERSHIP NEWSLETTER

Journey of Hope: Transforming Lives Through the Road to Hope Program

The Road to Hope (RTH) program is a joint initiative between the Center for Hospice Care/Hospice Foundation (CHC/HF) and the Palliative Care Association of Uganda (PCAU). Established in 2012, the program recognizes that effective palliative care extends beyond caring solely for a patient’s physical needs. The program is dedicated to support the children of patients, giving them the invaluable gift of peace of mind – knowing that their child will receive an education and means to support themselves after they are gone. The RTH program’s mission is to help orphaned or deprived child caregivers in Uganda receive the education they need to become productive young adults. In addition to educational support, the program addresses their medical needs, supports their emotional well-being and acts as a conduit for PCAU’s advocacy and community-level engagement. This strategy aligns with the World Health Organization’s [conceptual model for palliative care delivery](#), transforming PCAU into a community-centric force for holistic well-being.

At the heart of the RTH program lies the holistic approach to palliative care which focuses on the total wellbeing of the individual, their family and community. The program engages generous individuals to join this community and sponsor individual children. Through structured engagement with CHC/HF, RTH sponsors not only offer financial assistance but also establish personal connections with the children, fostering a sense of belonging. Thanks to the collaborative efforts of CHC/HF and PCAU and strengthened by the staff exchange visits, the partnership continues to grow, deepening relationships and offering opportunities to holistically support children on the RTH program.

In September 2023, the CHC/HF staff exchange visit coincided with [the 4th Uganda Conference on Cancer and Palliative Care](#). Karl Holderman, vice president and chief financial officer, Lacey Ahern, Global Partners in Care program director, and Denis Kidde, international programs coordinator participated in the conference. They also had several engagements with PCAU colleagues and some of the children on the RTH program. At the conference, a few recent RTH graduates supported conference logistics, and some exhibited their technical skills. Gertrude, who has just finished her vocational certificate in fashion and design, exhibited her exceptional work. Gertrude’s story demonstrates the impact of the RTH program. She has been supported by a sponsor and PCAU through her education, mentorship in her trade and is now being supported to settle back in her hometown in Kiboga District to practice her new trade. PCAU is providing her with start-up money, offering her the opportunity to be self-employed. Gertrude has gained a lot of experience from the structured mentorship initiatives organized by PCAU. Gertrude noted she “earns on a weekly basis, save some portion to support open up my own shop in the future and also use some of it to support my siblings in school...”



[Read more about the difference the Road to Hope program is making](#)

The Path for Disability in Palliative Care in Uganda

By Ethan Harned and Lena Dougherty

With the goal of ensuring all in Uganda have access to palliative care services, the Palliative Care Association of Uganda (PCAU) has partnered with multiple civil society organizations and conducted focus groups and surveys to evaluate the accessibility of palliative care services for persons with disabilities (PWDs). The results of this work will inform PCAU on where they should focus their efforts going forward.



While palliative care interventions continue to be impactful, the unique needs of PWDs during these interventions are often overlooked. The prevailing assumption that these patients, like other palliative care patients, can be adequately supported within routine practice standards, fails to acknowledge the multifaceted challenges they encounter. PWDs, who have long endured prejudice, bias and devaluation, face heightened vulnerability when utilizing palliative care services. Consequently, it is imperative to undertake an honest and thoughtful reevaluation of the standard model of palliative care in Uganda to address these unmet needs.

According to a [2019 report from the Uganda National Bureau of Statistics](#), approximately 14% of the Ugandan population over five years of age lives with at least one disability. The prevalence of disability in Uganda increases with age from 6.3% for children 5 – 17 years old to 61.5% for those over age sixty. With these statistics, accessible palliative care is even more important to consider. This article aims to shed light on the challenges PWDs face in Ugandan palliative care settings and the importance of recognizing and accommodating the specific requirements of these patients.

[Read more about PCAU’s work with PWDs](#)

Road to Hope Program

The Road to Hope program has at least nine unsponsored children. Your support can help an orphaned or deprived child caregiver in Uganda receive an education and other life skills necessary for them to become flourishing young adults. General donations to the program can be made at the link below. If you are interested in sponsoring a child or want to learn more about the program, contact [Denis Kidde](#).



[Support the Road to Hope](#)



Do you know someone who might enjoy reading about this partnership and palliative care in Uganda?

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