

# Focus on Compassion

Enhancing Access to Palliative Care Worldwide

## September is Childhood Cancer Awareness Month

Right now, millions of children around the globe need palliative care. Palliative care, which provides pain and symptom management, is essential for cancer patients – including children with cancer. According to the World Health Organization, "Palliative care for children represents a special, albeit closely related, field to adult palliative care." It is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on quality of life for the child and support for the whole family. The [International Children's Palliative Care Network \(ICPCN\)](#) advocates for children's palliative care to be acknowledged and respected as a unique discipline within health care systems and provided by suitably trained and qualified people to all children with incurable or life-threatening conditions and their families, regardless of where they live in the world.

In recognition of Childhood Cancer Month, we are sharing how some of our partners support pediatric cancer patients.

### Kawempe Home Care *Defying the Odds*

Muhamed is 18 years old and recently finished his advance-level studies (high school) with exceptionally good scores that rank him as one of the top students in Uganda. What is even more incredible is that this young man is undergoing treatment for cancer which he has been fighting since he was in primary 6 (grade school).



"I have 7 brothers and 6 sisters. I first noticed pain in my right ankle in 2013, which I managed with painkillers. I sought medical care due to the pain and swelling and it continued to get worse, so I finally went into hospital. My mother sold charcoal in order for me to get further treatment and also borrowed some money from friends to meet the costs of staying at the hospital. A biopsy was taken, and it confirmed I had liposarcoma cancer."

[Read all of Muhamed's story](#)



### The Rocking Horse Project *Rays of Sunshine*

The RHP received a referral last year for patient Sarah\* (not the patient's real name) diagnosed with osteosarcoma. The doctors explained that Sarah would be undergoing chemotherapy and the amputation of her left leg.

We continually kept in touch with the patient and her mother, checking on them regularly and visiting them during her admission in the hospital. We visited after she had undergone amputation of her leg and, along with the palliative care department at the hospital, provided the support they needed.

Sarah was a strong girl and rarely complained about pain or feeling sad. She accepted the amputation of her leg surprisingly well and was determined to continue life as normally as possible. She shared with one of the doctors that she had wanted to be a policewoman but knew that this may no longer be possible. When the doctor said she could have a prosthetic, she was delighted that her dream could still be a reality. With her approval, she had some sessions with a psychologist, and we were all glad she did as we felt this was necessary after this huge adjustment and moving forward.

[Read all of Sarah's story](#)

## Hats and Masks on for Children's Palliative Care Day #HATSON4CPC

By John Couri, GPIC Intern

Pediatric palliative care honors the entire individual – mind, body and spirit. It was in the summer of 2019 when I was first exposed to the field as a student researcher at the St. Jude Children's Research Hospital. Since then, I have integrated the principles of pediatric palliative care in my toolbox as I journey to become a compassionate healer.

One of these principles involves the act of listening. From my experience at St. Jude, I understand how powerful it can be to just sit and listen, bearing witness to others' stories. All humans have this extraordinary ability to help heal people around them, and part of it is rooted in their ability to listen deeply and to be fully present. The quiet strength of listening provides volumes of information about the mental and physical health of a patient, a friend, a family member or a child. It allows for them to tell their story. Unfortunately, within pediatric palliative care, many stories are not being heard. In particular, the story of limited access to pediatric palliative care services is still underplayed.



ICPCN's website has lots of social media graphics like this that you can use to help spread the word about the Hats on for Children's Palliative Care. Download the entire toolkit [here](#).

On October 8, we aim to change this through the "Hats on for Children's Palliative Care" (Hats On4CPC) campaign. HatsOn4CPC was initiated by the International Children's Palliative Care Network (ICPCN) in 2014. Every year, by wearing a hat on the second Friday of October, individuals raise awareness for the work of children's hospice and palliative care services worldwide. This year, individuals are wearing a hat *and* a mask to spread a few key messages: (1) every child deserves access to palliative care, and very few countries have the capacity to provide it; and (2) the services countries do have are underfunded and inadequate to meet the overwhelming need. As a result, thousands of children have poor quality of life and suffer from pain and other distressing symptoms that could be greatly improved with palliative care.

To enhance children's palliative care, we encourage you to join the HatsOn4CPC campaign! Those who participate should upload a photo of themselves in a hat and a mask to social media using #HatsOn4CPC. Be sure to tag @ICPCN and @Globalcare\_news so we can share your photos. Wearing a hat and a mask on October 8 is a simple way to show your support for pediatric palliative care. As we stand with all children and families in support of their palliative care journey, we also help narrow the gap between suffering and restoring. And just like a chain whose strength lies in its connectivity, the ones who listen to your story will offer powerful gifts in ways you never imagined.

### #GlobalPallCareHero

Do you have a palliative care hero you'd like to highlight? The #GlobalPallCareHero campaign runs through the end of September. Please send us your photos, videos, and stories no later than 30th September 2021. You may email these to [PCHeroes@globalpartnersincare.org](mailto:PCHeroes@globalpartnersincare.org) or send them to that email address via [WeTransfer.com](https://www.wetransfer.com)

If you are posting your own palliative care hero stories and photos, be sure to tag us using the hashtag #GlobalPallCareHero so we can amplify your gratitude.

Thank you to The Rocking Horse Project for sharing a #GlobalPallCareHero



[Learn more about #GlobalPallCareHero](#)



**LEAVE NO ONE BEHIND**  
EQUITY IN ACCESS TO PALLIATIVE CARE

World Hospice & Palliative Care Day  
**9 OCTOBER 2021**  
[www.thewhpca.org/world-hospice-and-palliative-care-day](http://www.thewhpca.org/world-hospice-and-palliative-care-day)

Find out more about World Hospice and Palliative Care Day 2021 and access resources to support your celebration of the day here:  
<http://www.thewhpca.org/world-hospice-and-palliative-care-day>.

### Advisory Council Member Highlight:



**Fatia Kiyange, MA**  
Deputy Executive Director at Center for Health, Human Rights and Development (CEHURD)

Fatia is currently the deputy executive director of Center for Health, Human Rights and Development (CEHURD). She has 20 years of experience in program development, leadership and management in the health and social service sectors at national, regional and global level.

[Read Fatia's full profile](#)

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Please share your stories with us so others may be inspired to act. We want to hear stories of your partnerships, research projects or other activities related to improving the lives of patients coping with life-limiting illnesses.

Email [info@globalpartnersincare.org](mailto:info@globalpartnersincare.org)

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