



Foundation for Hospices  
in Sub-Saharan Africa

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# Quarterly Report

## UGANDA PARTNERSHIP OFFERS REWARDS, CHALLENGES

**"WE DO AS MUCH AS WE CAN, AS WELL AS WE CAN, WITH THE LITTLE WE HAVE."**



*Roberta Spencer, Karen Smith-Taljaard,  
and Rose Kiwanuka*

**T**his past year, The Center for Hospice and Palliative Care, Inc. (CHPC) entered into a partnership with the Palliative Care Association of Uganda. This partnership was made possible by the Foundation for Hospices in Sub-Saharan Africa (FHSSA). After initial communication with Rose Kiwanuka, National Coordinator for the Palliative Care Association in Uganda (PCAU), CHPC's FHSSA Partnership Committee developed goals and set a clear agenda of what they hoped to accomplish during their March 2009 visit to Uganda. First and foremost, was to gain a deeper insight into how PCAU was working to ensure the dying and their families were finding compassion and relief from suffering at the end of life. Roberta and Karen, the two delegates chosen to make the initial visit, also wanted to assess the needs of the national association and see how CHPC could not only learn from them, but also provide support and assistance.

Like many countries in sub-Saharan Africa, Uganda faces enormous challenges in providing even the most basic palliative care. For those living in the rural villages of Uganda there is one doctor for every 50,000 people, and one doctor for every 32,000 people in the cities. Consequently, nurses assume a major role in health care. There is a high incidence of HIV/AIDS and cancer with limited facilities for treatment. For the population of 33 million people, there is only one radiation center for cancer treatment. Those fortunate enough to be able to travel to Kampala for radiation must deal with the fact that the machine is often broken or there may be frequent and often prolonged disruption of electrical power. Many patients lack the financial resources or the means to travel at all. All of these facts help contribute to Uganda's low life expectancy of 50 years for men and 52 years for women, and explain why more than half of the country's people are under the age of 15.

Despite these seemingly monumental issues, the Palliative Care Association of Uganda (PCAU) is a vibrant and active presence in the country; due largely to the leadership, energy, and devotion of Rose Kiwanuka, the person responsible for the vision: "Palliative Care for All in Uganda." Uganda has 80 districts, and approximately 32 of them have some form of palliative care structure. Many of the nurses have completed a nine-month intensive education program allowing them to prescribe medications for their patients.

Recognizing that much needs to be done, Rose is passionate about the need for training and education for all working in palliative care. She routinely makes contacts with local groups and/or anyone who can assist PCAU in their mission to increase the availability and quality of palliative care. During a site visit to the Natural/Traditional Healers of Prometra Uganda, Rose demonstrated these signs of

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*Group of health care workers from Natural/Traditional Healers of Prometra Uganda receiving palliative care training.*



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*Parade to celebrate the opening of the Arua branch of PCAU*

respect for cultural beliefs and traditions by working with them to integrate western medicine into traditional medicine. While many may find all this a tiring task, Rose operates with the simple philosophy that, “we do as much as we can, as well as we can, with the little we have.”

Our travels throughout the country validated the acute need for care, and also fostered an overwhelming appreciation for those who receive care. We visited families in village huts and homes, as well as staff and supporters. In Arua, located in the northwest part of Uganda and near the Sudan and Congo borders, there is a sense of immeasurable pride in what the hospice programs are doing and accomplishing; one step at a time.

Our arrival coincided with a planned district meeting. Hospital and community palliative care workers, many of whom traveled a great distance, gathered for morning educational sessions and the public “launch” of the Palliative Care Association of Uganda, Arua branch. With a mid-day parade through the streets, PCAU’s presence generated large community awareness. Public officials spoke after lunch, affirming their support of palliative care.

The basic need for comfort care became obvious to us through our contacts with the Aruan people. One nurse said, “I know about this care by using it and now I am promoting it.” Another worker added, “When my mother died comfortably in my arms and not in the hospital, it was at that moment I believed in palliative care.”

We not only experienced the beauty of the people, but the beauty of the culture and the land. Our trip to Rays of Hope Hospice, Jinja provided us the opportunity to see fields of sugar cane and tea and to enjoy scenery at the Mouth of the Nile. Our interactions with the staff, patients, and their families, both in the hospitals and at



*Group meeting to discuss palliative care*

home, reaffirmed the need for continued outreach services and training in palliative care. Commitment and dedication are strong components of all the programs as well as the determination to make comfort viable for as many people as possible.

The same qualities hold true for the time we spent at a day program at Hospice Africa Uganda. Adults and children, physically able to travel, came together for companionship, an opportunity to see

a doctor, to receive a meal, and to work on creative projects as their energy level permitted. They were welcoming, gracious and interested in our mission. They made us feel humbled by how much we have and how little they ask from us.

We began our journey with four main goals: establish a relationship with Rose and become familiar with other organizations working with PCAU; learn more about PCAU, particularly Rose’s expectation(s) of how CHPC can assist; review financial needs and clarify funding; and, identify ways of collaboration around education and training. We believe we accomplished our goals, but many challenges lie ahead of us. Exploring opportunities for fundraising, developing ways to assist in training, and helping prioritize needs for PCAU are a few of the many issues that we will address in the weeks and months ahead. Yet, such challenges bring opportunities.

Seeing the pride with which workers carry on their day-to-day tasks, laboring with few resources, traveling great distances over rugged roads to reach just one person, and overwhelming numbers of individuals needing help is truly inspirational. This is our hospice’s affirmation as to why we made the decision to establish a FHSSA partnership and why we believe it is a wonderful match. ☯

*By: Roberta R. Spencer and Karen Smith-Taljaard, The Center for Hospice and Palliative Care, Inc., South Bend, Indiana; Rose Kiwanuka, Palliative Care Association of Uganda; and Alexandra Shade, Foundation for Hospices in Sub-Saharan Africa.*



## INTERVIEW WITH FHSSA'S NEWEST BOARD MEMBER: LIZ GWYTHYR

### Can you describe a bit of your history and background?

I was born in Zimbabwe and grew up in the eastern Highlands of this very beautiful country. I studied medicine at the University of Cape Town and returned to work in Zimbabwe where I was married. We moved to South Africa to a fruit farming region outside Cape Town in 1983 where I worked as a General Practitioner and where my two children Kate and Andrew were born. We moved into Town in 1988, and in addition to working as a GP, I started volunteer work for the local hospice. I soon realized that I did not have the knowledge or skills for Palliative Care and registered to study a distance-learning diploma through the University of Cardiff, Wales and then MSc in Palliative Medicine. Becoming more involved in hospice work, in 2001, I accepted a position as CEO at St Luke's Hospice in Cape Town, at the same time as starting a part-time teaching post at the University of Cape Town teaching a post-graduate distance-learning diploma and master's degree in palliative medicine assisted for the first three years by the University of Cape Town.

### How did you get involved with Palliative Care and why is it so important for South Africa?

My involvement started with afterhours support for our local hospice with a passion to learn more and provide quality palliative care for patients and families affected by life-threatening illness.

I became involved with the Hospice Palliative Care Association of South Africa (HPCA) in 1998 while I was working as a GP and volunteering my clinical services at Helderberg Hospice in Somerset West, Cape Town. I worked initially on the Patient Care and Education subcommittee and then took up a post as National Education & Research Manager for HPCA, when the organization first received a grant from the US government through the President's Emergency Plan for AIDS Relief. HPCA then created the post of

CEO and I was appointed to this position. In 2007, I received two awards - the SA Medical Association's Gender Award for Human Rights in Health and the SA Institute of Health Managers Leadership in Health Systems Award.

My position on the boards of NHPCO and FHSSA is of great value to me and to HPCA in broadening my experience and vision for palliative care within South Africa and internationally. Palliative Care is important in any society. In South Africa, where 85% of the population does not have health insurance, the state health system is overburdened, patients seek services late - often with incurable cancer and there is a high prevalence of HIV (28%). Hospices provide care free of charge and often are the entry point for HIV positive people to access antiretroviral treatment. Hospices are involved in prevention programs, treatment support and palliative care for people affected by life-threatening illness as well as palliative care in terminal illness.

### What is happening now at HPCA and what opportunities do you see in the future for Hospice and Palliative care in South Africa?

HPCA's vision is "Quality Palliative Care for All." Our mission is to promote quality of life, dignity in death and support in bereavement to all those living with life-threatening illness through the support of member hospices and partner organizations.

Currently, we estimate that approximately 17% of people who died in 2007 received palliative care through our hospice services. HPCA has a strong development strategy with seven working groups focusing on palliative care development. These are advocacy, education and research, finance and resource development, monitoring and evaluation, organization development, patient care, and pediatric palliative care. We are addressing the following questions: what was the experience of the other people who died? Was there quality care? Were their families



assisted? What happened to the children? We have an estimated 2.4 million orphans in this country and have started programs to support orphans and vulnerable children including facilitating their staying in school.

We have assisted many organizations in the integration of palliative care into their services and have grown from 52 members in 2004, when US government funding first became available, to 202 hospice sites in 2009. We have accredited training programs for different staff groups from community caregivers to interdisciplinary palliative care professionals.

FHSSA has been a very important partner for HPCA in assisting our hospice development with skill sharing between US and SA hospices and generous funding from US partner hospices which assist SA hospices in providing palliative care within their communities.

We have recently been approached by the national Department of Health to draft a Palliative Care Strategy for South Africa and have established an Alliance for Access to palliative care with many different role players to develop this strategic document. HPCA staff members also contribute to palliative care development in Africa working with the African Palliative Care Association and internationally through the Worldwide Palliative Care Alliance. HPCA will continue to focus on hospice development but also on palliative care in the formal health care sector to ensure palliative care provision in hospitals and clinics as well as in the NGO sector. ☺



## SUPPORT FOR FHSSA BY WALKING ACROSS IOWA

Completing 360 miles in 28 days, the Tuites walked across Iowa from the Missouri River to the Mississippi River in loving memory of Micheal's mother, Elizabeth (Betty) Tuite who died in 2006. Micheal and his wife, Jennifer, recognized that the hospice care she received added great dignity to the end of her life and committed themselves to finding a way to give back. Their journey is one of love and remembrance and a wonderful story of healing and courage.

"Friends asked us, why hospice in Africa?" Jennifer shared. "We appreciate what [hospice] means to people and know people are sympathetic to the cause. But we were also aware how much further the money raised would go towards care in Africa."

Backpacking and camping across Iowa, the Tuites raised nearly \$9,000 in support of FHSSA. For Jennifer, this walk was an opportunity to return to and experience her home state. Over the past 10 years, she has been living in Micheal's home country of Ireland. Along the route, they had the opportunity to visit with and share their story with local hospices, churches and civic organizations, meeting new friends and visiting familiar faces.

"Along the way, people asked, why Iowa? We found it easy to explain, since Iowa is as beautiful as anywhere else. It was a connection with the meaning of family since my family has lived here a long time," said Jennifer. "As we were walking, we realized the huge need for services in rural communities...just like the need a continent away in Africa," said Micheal.

Their walk began the afternoon of May 17, following the program, "Why We Should Care: the HIV/AIDS Pandemic in Sub-Saharan Africa" at the Betty Strong Encounter Center on the Sioux City's riverfront. The program's main speaker was Louise Stobart, director of Howick Hospice, Kwa-Zulu-Natal, South Africa. She discussed the HIV/AIDS pandemic in South Africa and how their FHSSA partnership with Hospice of Siouxland has and continues to help her community.

Linda Todd, Director of Hospice of Siouxland explained, "our partnership with Howick Hospice is a great opportunity for our organization to reach out beyond our corner of the world and make a difference for others in a far-off country. Their needs are tremendous. Our monetary donations, program resources and support do make a difference. Our lives are enriched by this partnership."

John Mastrojohn, Vice President, FHSSA, attended the event in Sioux City. "We are so grateful, to have the opportunity to participate in this event", said John. "Jennifer and Micheal are a gift to us and to all those who will benefit from their generosity and commitment".

If you would like to make a contribution to the Tuites River to River Walk, please visit [www.firstgiving.com/rivertoriver](http://www.firstgiving.com/rivertoriver).



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## 10 YEARS OF PROGRESS, A FUTURE OF HOPE

FHSSA will celebrate 10 years of partnerships and international relationships during the National Hospice and Palliative Care Organization's 2009 Clinical Team Conference.

This celebration will be held on Friday, September 25, 2009 at the Hyatt Regency in Denver, Colorado. The evening will include wine tasting, hors d'oeuvres, African music, and a silent auction. All proceeds from the event will go towards the continuation of FHSSA's efforts to improve hospice and palliative care availability in Africa. Tickets can be purchased for \$60 with conference registration and \$75 for those not registered for the conference.

To register to attend, contact NHPCO's member services at 1-800-646-6460. If you would like more information about this event, please contact Erinn Nanney at (703)647-6684 or [enanne@fhssa.org](mailto:enanne@fhssa.org).