



FOCUS ON COMPASSION

a quarterly newsletter



In early March 2011, the first group of six staff from three ELCT hospitals completed their orientation on oral morphine use. They concluded their training by carrying home their first supply of five liters of oral morphine, which was available for patient use immediately. Here they pose with their trainers and colleagues.

Morphine Breakthrough in Rural Tanzania

As a result of training and advocacy efforts fueled by the CHAT project, people in rural Tanzania now have access to oral morphine

Tanzania remains one of many countries where the use of morphine for treatment of pain is extremely low despite tremendous need driven by both the HIV/AIDS epidemic and a growing incidence of cancer. With a population of over 40 million people, only 750 grams of morphine powder were imported in 2009 and 1647.7 grams in 2010, according to the Tanzania Food and Drug Authority (TFDA). In comparison to other countries, Tanzania's morphine consumption is negligible.

Many factors contributed to poor access of morphine in Tanzania, including the failure of many hospitals to meet TFDA criteria for approval. For years, morphine has only been available in four sites in the country: the Ocean Road Cancer Institute (ORCI), PASADA, Muheza Hospice, and Selian Hospice. All of these centers are urban or semi-urban, leaving Tanzania's rural population with extremely limited access to this crucial painkiller.

Role of FHSSA's CHAT Project

In 2006, FHSSA was awarded a grant from PEPFAR funding through USAID called the Continuum of Care for People Living with HIV/AIDS in Tanzania – CHAT. The implementing partner in Tanzania was the Evangelical Lutheran Church in Tanzania (ELCT). The goal of the project was to incorporate palliative care into ELCT's hospital

system as well as a network of rural home based care providers. The idea was to replicate the successful program at Selian Hospice -- including the use of oral morphine for pain. The CHAT project worked with 13 rural ELCT hospital sites.

With CHAT funding, teams of nurses and doctors were trained in palliative care – including pain assessment and management. The clinical staff understood the need to have access to oral morphine and was encouraged to apply for permits. Matema Hospital in the Southern Zone persevered in their effort and was successful in obtaining a permit from TFDA in January 2011.

A group of key palliative care organizations including Tanzanian Palliative Care Association (TPCA), ORCI, and ELCT Palliative Care program built on this success and scheduled a meeting with TFDA authorities in February 2011. They shared their challenges in obtaining permits for hospitals and were provided with very helpful clarifications about TFDA's regulatory role and the misconceptions shared among the palliative care providers.

Following TFDA's instructions, all CHAT sites have managed to secure permits for procurement and use of oral morphine. In addition one government referral hospital (Kagera) and Shirati Mennonite Hospital also received permits. ORCI, Tanzania's only cancer treatment center, agreed to provide training to the recipient hospitals.

This "breakthrough" marks the very first time that widely scattered rural health facilities in Tanzania will be able to procure and use morphine for severe pain management.



Stacy Orloff of Suncoast Hospice (center) accepts the award from Shareefah Sabur, FHSSA board president (right) and Dr. Faith Mwangi-Powell of the African Palliative Care Association. In one part of their application, Suncoast officials wrote: “We feel that our partnership is a living entity and presence for us on a daily basis. It’s how we live our mission in the world—a priority to Suncoast Hospice.”

Suncoast Hospice (Florida) and Hospice of the Witwatersrand (South Africa) Receive the Global Partnership Award from FHSSA

Award Recognizes Their Outstanding Partnership Efforts to Improve Palliative Care

FHSSA presented the first FHSSA Global Partnership Award to Suncoast Hospice (of Clearwater, Florida) and their partner, Hospice of the Witwatersrand in South Africa. The award was announced April 7th during the National Hospice and Palliative Care Organization’s (NHPCO) Management and Leadership Conference in National Harbor, Maryland.

The award was established to recognize the exemplary work of one US/African partnership. The selection committee looked for a partnership that demonstrated leadership and innovation—and significantly contributed to the sustainable development of hospice and palliative care in Africa. All FHSSA program partners were invited to self-nominate for the inaugural Global Partner Award in recognition of work they accomplished in 2010. FHSSA received over a dozen applications.

“Selecting a winner was an extremely difficult decision to make,” said John Mastrojohn, FHSSA’s executive director. “The selection committee was deeply impressed with the applications we received. It is very clear that hospices programs in the US and their counterparts in Africa take their partnerships very seriously and work hard to make them meaningful and valuable. For this year, the decision to give the award to Suncoast and Witwatersrand was based on the sheer depth and breadth of their joint activities.”

Cash Prize

The award came with a \$500 donation to the African hospice partner and was supplemented by two additional donors who announced that they would each personally match that donation, bringing the entire gift to \$1,500.

Two Other Partnerships Recognized

Certificates of recognition for two other partnerships went to: 1) Gilchrist Hospice (Maryland) and Nkoaranga Lutheran Hospital Palliative Care Program in Tanzania and 2) Arkansas Hospice and Seke Rural Hospice in Zimbabwe. “Both of these partnerships had very strong components; the selection committee felt compelled to recognize their notable achievements,” said Mastrojohn.



Robin L. Stocksdales (center) accepted the special recognition on behalf of Gilchrist Hospice in Maryland. Their partner is the Nkoaranga Lutheran Hospital Palliative Care Program in Tanzania



Arkansas Hospice is partnered with Seke Rural Hospice in Zimbabwe. Here, Deb Schaefer, chief clinical officer at Arkansas Hospice, accepts the special recognition award.

FHSSA and the African Palliative Care Association Launched a Pain Management Initiative in The Gambia, Kenya, and Malawi

The Initiative is Funded by More Than \$220,000 Donated to FHSSA



The goal is to improve pain management among palliative care patients receiving care in hospitals in those countries. In February, 2011 the entire launch team met for two days of intense planning work in Kampala, Uganda. Representatives from all three countries joined APCA staff. FHSSA was represented by John Mastrojohn, executive director.



The team from Malawi is pictured with John Mastrojohn, FHSSA executive director (back row) and Faith Mwangi-Powell, APCA's executive director (second from right). Funding for the initiative was provided by Astellas Pharma US, Inc., AstraZeneca Pharmaceuticals LP, Daiichi Sankyo, Inc., Endo Pharmaceuticals Inc., Lundbeck Inc, OSI Pharmaceuticals Inc., Pharmaceutical Research and Manufacturers of America (PhRMA), Grünenthal, and The Brin Wojcicki Foundation.



This is the team from Kenya. The three countries were selected because they each have well-established national palliative care organizations, strong clinical leadership, historical success with related projects, and sound professional relationships with APCA and FHSSA staff and leadership.



The team from The Gambia worked on their plans. All three countries will focus on three objectives: 1) creating support for palliative care delivery among hospital management/administrators; 2) training hospital physicians in pain assessment and management, with a central focus on opioid use, and 3) sensitizing other health care workers in the hospitals and community to support palliative care service delivery.

Quote from Day Two of Launch

“Yesterday was a new beginning in my life... I have the knowledge now that pain must be addressed... we need to find a way.”

—Petronilla Akello Odero, Kenya



While in Uganda, John Mastrojohn made home visits through two hospices. Here is the team from Hospice-Jinja, located in the town of Jinja, on the shores of Lake Victoria. He also visited patients through Kawempe Home Care in Kampala, Uganda's capital city.

Palliative Care Nursing Scholarships Available for Nurses in Africa

A Generous Anonymous Donor Makes the African Palliative Care Nursing Scholarship Fund Possible

The need for nurses trained in palliative care in Africa is enormous, particularly in rural areas where nurses are typically the only healthcare professionals available. To help meet this need, FHSSA and the African Palliative Care Association (APCA) have created the African Palliative Care Nursing Scholarship Fund. The fund was established by a generous anonymous donation. It was given in honor of Kath Defilippi, APCA's founding board chair, in

recognition of her leadership and achievements as a hospice and palliative care nurse in Africa.

The fund will support nurses' education and training in a palliative care program over a period of two years. The fund will cover training and related travel costs (within Africa) at various levels up to a maximum of \$4,000 (US) per person. The scholarships are for registered nurses residing in Africa who can provide documentation that they will be able to provide palliative care in their country after training.

Demand is High

The scholarship's availability was announced in late March. By early April, more than 200

applications had been received by APCA, which is handling the review process, with input from FHSSA. With the current level of funding, it is expected that a total of 11 nurses will benefit.

"With additional financial support from new donors, the Fund can have an even greater impact," notes FHSSA Executive Director John Mastrojohn. "We are eager to talk to individuals who want to have a direct connection to palliative care in Africa. By funding the scholarship program, donors will have the opportunity to have a positive effect on individual nurses in Africa. The need is great—and the rewards are as well."

Individuals interested in learning more about supporting this program should contact FHSSA Coordinator Erinn Nanney, at enanne@fhssa.org or 703-647-6684

Heartfelt Thanks from the Palliative Care Association of Uganda to Their Partner, The Center for Hospice Care (in South Bend, IN)

We are happy to share with you this message that Robert Spencer, a volunteer from the Center for Hospice Care in South Bend, IN sent to Mike Wargo at the Center. She spent three months this winter working with Rose Kiwanuka, national coordinator at the Palliative Care Association of Uganda (PCAU). The financial support of the Center was vital in launching a new palliative care district in Uganda. Employee donations funded the training of two new palliative care providers.

March, 2011

Hi Mike,

This is a special message for you and the Center for Hospice Care!

The launching of Kibaale as a Palliative Care District took place today. It started late due to heavy rains, but despite the muddy roads the parade took place through the roads of town ending at the Starlight Hotel with an afternoon of speeches and testimonies about the positive effects of palliative care. There was also some entertainment from the band who led us through town and a drama group who made up songs of thanks for hospice and acted out someone in pain and the need for palliative care. This is really a remote area and the people in attendance have so much pride about what has taken place for them.

The Center for Hospice Care was mentioned very often this afternoon with individuals expressing gratitude for the partnership and support of the development of palliative care throughout Uganda. All the officials from town were present from the Commissioner of Health who traveled from Kampala (who remembers you and me from our visits and contacts), to the District Medical Director, Director of Health, Director of Infectious Disease, just to mention a few.

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Words from Roberta Spencer, Volunteer with PCAU

I was privileged to spend three months in Uganda (January 17-April 17, 2011) working with Rose Kiwanuka and the Palliative Care Association of Uganda (PCAU). I came as a volunteer from the Center for Hospice Care, South Bend, Indiana. It was an incredible experience and I met so many dedicated and caring people. Rose is remarkable. The Center for Hospice Care is involved in so many ways with PCAU. The partnership is an example of a perfect match made by FHSSA!

There is still so much to be done, but those involved in hospice and palliative care working to meet the current and future needs, are energized by the accomplishments they have achieved. Those need to be celebrated!



Roberta Spencer (right), longtime staff member at the Center for Hospice Care spent three months in Uganda earlier in 2011, working with the staff of the Palliative Care Association of Uganda. She found working with PCAU national coordinator, Rose Kiwanuka (left) incredibly rewarding.



On the day of the launch of the new palliative care district, there was a parade, with banners. The new palliative care providers, and their colleagues, held the PCAU banner.

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I assured them that I would express their “sincere appreciation” to the Center For Hospice Care for all that was done to particularly assist their district with the recent support for the education of our two new palliative care providers, recent support for the education of our two new palliative care providers who were introduced at the meeting.

The Commissioner stated, “I feel we are one and that differences do not separate us.”

One of the participants said, “We may not have much, but we do have appreciation and thanks to offer to you. Please extend our wishes.” Everyone acknowledged the partnership in some way. So many came up to me during and after lunch to say “thank you!”

FHSSA “Ambassadors” Meet for the First Time and Get Energized About Their Charge

In a New Program, Experienced American Partners Will Educate Other Hospices in Their Regions About the Benefits of Partnering Through FHSSA

There is a waitlist of African hospices wanting American partners. There are hospices across the United States who probably would sign up for the program, if they knew more about it. And although our website and this newsletter do a good job of explaining the partnership program, nothing can take the place of face-to-face conversation with an experienced hospice partner.

Therefore, in order to extend the reach of FHSSA into even more American hospices, we have created the “FHSSA Ambassadors.” These Ambassadors represent US partner hospices and can speak knowledgeably and powerfully about the challenges and opportunities of being a partner. In addition to recruiting hospice partners, Ambassadors will also work to recruit new champions to support palliative care in Africa, through universities and other organizations.

During the National Hospice and Palliative Care Organization’s 26th Management and Leadership Conference in April, the first set of Ambassadors met for their initial training. All participants had a great deal of wisdom to share with each other about what partnering

offers a hospice and in particular what impact travel to Africa has on individuals. Stacy Orloff said, “As a human being, my life has been so enriched by deep and abiding friendships I never would have had.”

Following that discussion, FHSSA staff members Shelley Smith and Erinn Nanney used a sample PowerPoint presentation to walk Ambassadors through the various talking points they might consider with their audiences.

Another training will be held in San Diego in October, during NHPCO’s Clinical Team Conference, to expand the program’s reach into Western states.

“I am excited about the potential the Ambassadors have to identify new partners and champions and help us expand our program. We are looking forward to supporting the Ambassadors in their efforts,” says Smith, director of FHSSA.

If your hospice or other organization would like to have a presentation by an Ambassador, contact FHSSA Director Shelley Smith, at ssmith@fhssa.org or 703-647-6695.

FHSSA Ambassadors Trained in April, 2011

- **John Johnson**
Hospice of the Bluegrass
- **Margo Nixo**
Hospice of Siouxland
- **Cynthia Roy-Squitieri**
Regional Hospice of Western Connecticut
- **David Simpson**
Hospice of the Western Reserve
- **Stacy Orloff**
Suncoast Hospice
- **Steve Taylor**
Hospice of Washington County
- **Mike Wargo**
Center for Hospice Care

“Hot Spots and Black Holes” and “System Strengthening”

Dr. Faith Mwangi-Powell, Executive Director of the African Palliative Care Association, Spoke to Guests at the 2011 FHSSA Breakfast of Champions

People who rose early on the morning of April 7 to make it to the FHSSA Breakfast of Champions were rewarded with a stirring speech by Dr. Faith Mwangi-Powell, executive director of the African Palliative Care Association (APCA).

Dr. Mwangi-Powell first spoke about “hot spots and black holes”—her way of describing things going well in Africa regarding palliative care and areas of great ongoing concern.

The “hot spots” were significant and included:

- **The Kenyan government allowing 11 hospitals to develop palliative care**
- **In Malawi and Kenya, great strides are being made in the intergration of palliative care into the curriculum for doctors and nurses**
- **Rwanda launching a nationwide palliative care policy in April 2011**
- **Swaziland also launching a palliative care policy, including monitoring and evaluation activities.**

The black hole is gaping: in 22 African countries, palliative care is simply not known. And, while Côte d'Ivoire was making strides, those are now on hold as that country faces political turmoil. It is an understatement to say that enormous work remains to be done to bring palliative care to everyone who needs it on the African continent.



Dr. Faith Mwangi-Powell spent almost two weeks with FHSSA staff, attending NHPCO's Management and Leadership Conference, meeting with funders, and working on future plans for FHSSA and APCA. Here, she addresses guests at the “Breakfast of Champions” on Thursday, April 7.

System Strengthening

Dr. Mwangi-Powell characterized the situation in Africa as “less money/more need.” She described the changing face of international aid, which includes flat-lining of USAID/PEPFAR funding, closing of major funders such as the Diana, Princes of Wales Fund, and overall budget cuts. Dr. Mwangi-Powell said African organizations must figure out how to be innovative and creative.

To her, the answer lies in positioning palliative care into the “system strengthening” agenda. By this she means, switching from asking for palliative care dollars and instead, arguing boldly about what palliative care can do for the health system.

FHSSA's Role

Dr. Mwangi-Powell outlined what she sees as the role of FHSSA partners:

- **Collaboration and networking**
- **Funding**
- **Exchange of ideas, innovation and friendship**

She ended her remarks by noting that FHSSA has become an important ally of APCA's. In acknowledging with appreciation the relationship between the two organizations, Dr. Mwangi-Powell highlighted her connection to John Mastrojohn's, FHSSA's executive director. She said, “It's a lonely road I'm on: it's difficult, draining, and tough. John has become an important part of my support system. It's also two-way; if John has problems, he will email me and ask for advice.”

As John Mastrojohn thanked Dr. Mwangi-Powell for her presentation, he echoed her sentiments, and expressed his appreciation for the APCA/FHSSA relationship

The Foundation for Hospices in Sub-Saharan Africa is now doing business as FHSSA.



FHSSA

Compassion has no borders

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