

**FHSSA***Compassion has no borders*

Quarter 2 – 2013

FOCUS ON COMPASSION

a quarterly newsletter

Third Annual FHSSA Global Partnership Award Was Presented on April 25

Center for Hospice Care/Hospice Foundation of Indiana and the Palliative Care Association of Uganda are the 2013 Winners

The third annual FHSSA Global Partnership Award was presented to Center for Hospice Care/Hospice Foundation of South Bend, Indiana and Palliative Care Association of Uganda on April 25 during the National Hospice and Palliative Care Organization's (NHPCO) Management and Leadership Conference.

The Global Partnership Award is an opportunity to recognize the outstanding efforts of a partner that went above and beyond the expectations of a partnership. The award winner is selected based on creativity in fundraising, partner collaboration, staff contribution and commitment, and community outreach and involvement. The award comes with a \$500 donation to the African hospice partner.

"Center for Hospice Care/Hospice Foundation has shown what a tremendous impact one partnership can have. The creativity and commitment they have made to the Palliative Care Association of Uganda will have a lasting effect on the patients and families needing palliative care and also to the dedicated health care workers who work tirelessly with limited resources to provide that care," said John Mastrojohn, executive director of FHSSA.

Center for Hospice Care/Hospice Foundation, which raised over \$25,000 in 2012, partners with the Palliative Care Association of Uganda (PCAU). The review committee was impressed with CHC/HF's award application on many levels, including their unique and creative fundraising efforts and involvement in advocacy efforts on the national level in Uganda, their dedication to finding a new home for PCAU headquarters, and their financial support for scholarships to train Ugandan healthcare workers in palliative care.

"Our FHSSA partnership has been rewarding and meaningful for our staff, our board and our volunteers. It has been our privilege to be partnered



Members of the Okuyamba film crew and Rose Kiwanuka during filming of the award-winning short documentary.

with PCAU. But it's so much more than a partnership. For us, faraway places have come closer, the planet has become smaller, and our own hospice family has grown in the best ways possible," said Mark Murray, president and CEO of CHC/HF.

Some of the 2012 highlights of this award-winning partnership include:

- **Okuyamba.** In collaboration with faculty and alumni of University of Notre Dame Film, Television and Theatre Department, CHC/HF created an award-winning documentary that offers a glimpse at the astounding challenges facing terminally ill people living in Uganda and the monumental issues PCAU encounters in its daily work. The film has helped increase world-wide awareness of the suffering of patients with life-limiting illness in Uganda and throughout Sub-Saharan Africa. CHC/HF has made the film available to hospices across the country to use in awareness-raising and fundraising efforts locally.
- **PCAU Building Fund.** One of PCAU's top strategic priorities for 2012 was to find a sustainable office space for its headquarters. Proceeds from CHC/HF's World Hospice & Palliative Care day event were directed toward acquiring that space.
- **Partner Visits.** CHC/HF provided funding for PCAU Country Director, Rose Kiwanuka to visit the U.S. In addition to meeting with CHC staff on a number of initiatives, Rose also attended NHPCO's MLC near

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Washington, DC. In return, HF's COO Mike Wargo and volunteer Roberta Spencer traveled to Uganda to work on a number of partnership projects. Their visit included meeting with Members of Parliament to advocate for palliative care in Uganda.

- **Scholarships.** CHC/HF's fundraising efforts have also supported two scholarship programs: The Clinical Palliative Care Course Scholarship and the Road to Hope Program, which provides financial support for child care givers to attend school following the death of a parent.

Mike Wargo, COO of Hospice Foundation noted, "It's been said that pain knows no boundaries. Through our partnership with PCAU and through making our film *Okuyamba* available as an education and fundraising tool, we have also found that compassion and caring know no boundaries."

FHSSA congratulates Center for Hospice Care/Hospice Foundation and PCAU for their outstanding commitment to their partnership and for making a lasting impact on palliative care in Africa.

FHSSA Partnership Update

Two New Partnerships Were Formed in March

We proudly welcomed the formation of these two new partnerships.

Global Palliative Initiative and Mulanje Mission Hospital: Malawi

This partnership is a landmark for FHSSA, as the inclusion of the Global Palliative Initiative (GPI), a Canadian healthcare workers group, will be the first Canadian-African pairing in FHSSA's history. The GPI is a group of seven palliative care physicians and nurses from McMaster University in Ontario, Canada who have been seeking for two years an opportunity to partner with an African hospice. In March 2013, their search came to an end by partnering with Mulanje Mission Hospital (MMH) in Malawi.



Founded in 1928, MMH incorporates a palliative care staff of three full-time and five part-time members that works in conjunction with a team of 200 volunteers. The program provides outpatient, inpatient, home-based and pediatric palliative care. MMH has also recently been added as a site for clinical placements in palliative care for doctors and nurses who have had post-degree training in palliative care. With the aid of GPI, MMH has a wonderful opportunity to continue developing into a leader of palliative care in Africa.

VITAS Delaware and Little Hospice Hoima (LHH): Uganda

VITAS Delaware will be the 21st VITAS hospice program to join FHSSA. VITAS Delaware had considered joining FHSSA for some time, but



only recently felt that they were ready to make the commitment. Now hospice staff and volunteers will begin the process of developing a strong relationship with their new African partner, Little Hospice Hoima (LHH).

Based in Western Uganda on the shores of Lake Albert, LHH started in 1998 as a satellite site for Hospice Africa Uganda (one of the first hospices in Africa). LHH's palliative care program consists of 17 staff members who offer home care, consultation in the referral hospital, and a day care at the hospice and in the community. In addition, they have a large palliative care education program for volunteers and health professionals in Hoima and surrounding districts.

Results of the 2012 FHSSA Partnership Survey Reveal Impact on the Continent

330,000 People Were Touched by Partnership Programs

Every year, FHSSA partners are asked to fill out a survey in order to track the successes, failures, and challenges of the Partnership Program. The 2012 survey painted a picture of a program that continues to demonstrate significant impact in the development of palliative care in Africa. Last year alone, our Partnership Program touched the lives of over 330,000 affected by life threatening illnesses.

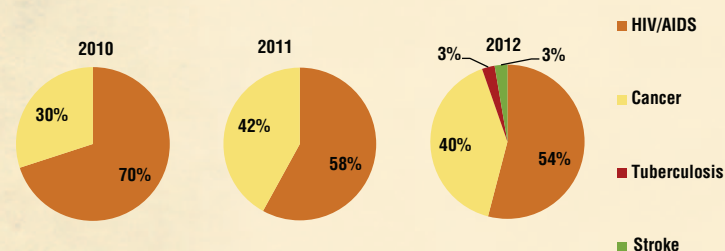
Who Took the Survey

Different surveys were developed for both African and U.S. partners. These surveys were distributed to all 92 FHSSA partnerships in January 2013. The U.S. and African surveys garnered response rates of 59% and 53% respectively. We thank all the partners who participated.

A Picture of Palliative Care in Africa

While the HIV/AIDS epidemic remains a significant problem for Africa, the impact of other diseases, most notably cancer, has been growing. Indeed, 2012 was the third year in a row in which the percentage of hospices identifying HIV/AIDS as their most frequent diagnosis has fallen:

Identified Primary Diagnosis of FHSSA African Partners 2010-2012



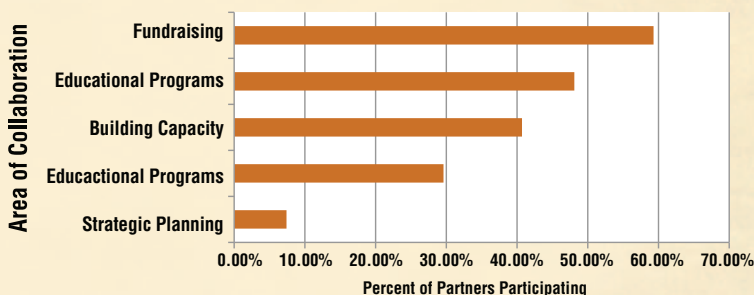
Impact of the Partnership Program in 2012

This year, FHSSA partners raised nearly half a million dollars to support thousands of African hospice staff, and volunteers provide needed services to hundreds of thousands of patients and their families throughout the continent. Below is a breakdown of those supported by the Partnership Program in 2012:

- Total Donations to be Wired Directly to Africa: \$462,875
- African Hospice Employees: 2,134
- Hospice Volunteers: 5,183
- Hospice Patients: 66,000

In addition to the impact on service providers, the Partnership Program provided valuable collaborative support in numerous areas. The chart below demonstrates other areas where FHSSA U.S. partners were active.

Most Common Partner Collaborations



Considering the support that is transferred between the partnerships, it is not surprising to see a high level of satisfaction with the program. In fact, almost 90% of African partners consider their partnership to be "important" to the operation of their organization.

While the partnership program has been important for the African partners, U.S. partners have also benefited. In fact, over 75% of U.S. FHSSA partners reported that the partnership had made an impact on their organization. This impact is seen in many different ways:

Impact of Partnership on US Partners



As demonstrated by the 2012 annual partnership report, the FHSSA Partnership Program continues to play a significant role in the development palliative care in Africa while also benefiting U.S. partners. As the face of palliative care in Africa continues to change, there is little doubt of the importance of the Partnership Program in its continued development.

One Vehicle Can Make a Big Difference in Zimbabwe

VITAS Innovative Hospice Care of the Inland Empire Raises Funds to Buy a Truck

One of the most significant challenges facing palliative care providers in Africa is lack of transportation. A large portion of African patients live in far-flung rural areas, cut off from public transportation or even roads. Thus, ensuring that health care workers are equipped with proper means of transportation is extremely important.

This situation certainly held true for Nyadire Hospital Palliative Care Program located in Zimbabwe. According to Dr. KM Tshiani of Nyadire, "Following up with patients and caregivers was difficult. Patients live in scattered directions in various different locations in villages." The result of this scattering of patients was that a nurse could only attend to a few patients at a time. In a region where the need is so great, medical workers must be able to attend to as many patients as possible.

Two organizations came together to help Nyadire Hospital Palliative Care Program address this crucial need. Together, VITAS Innovative Hospice Care of the Inland Empire (a FHSSA partner) and the Nyadire Connection (a faith-based American non-profit organization) purchased a new 4x4 truck. Such a sturdy vehicle is necessary for the rugged terrain.

According to Tammy Shewell, a social worker at VITAS of the Inland Empire, they first identified the goal after a conversation with Dr. Tshiani



In Zimbabwe, Dr. Tshiani (far right) and other members of the Nyadire Hospital Palliative Care Program staff toast the arrival of their new vehicle with sodas.

about three years ago. In the subsequent years, the hospice conducted several fundraisers, including yard sales, raffles, and an auction raising nearly \$24,000. This money was then combined with a large donation by the Nyadire Connection to cover the additional costs.

The impact of the new truck has already been felt. According to Dr. Tshiani, "After the vehicle came, the situation has completely changed...the nurses can now attend to many patients in a short time. Patients and relatives are happy to see a team visiting a patient with a new vehicle."

Dr. Tshiani made note of one patient who was "bedridden for a long time due to AIDS, but became physically strong under our palliative care program. Then she suddenly developed psychosis, which made it difficult for her relatives to assist her, as she refused to come to hospital. With the vehicle, it was easy to reach her and integrate her in to a mental health program by a visiting mental health team."

Host Okuyamba in Your Community

Create Awareness and Raise Funds

The Center for Hospice Care and their FHSSA partner, the Palliative Care Association of Uganda have created a multi-award-winning 30-minute documentary on palliative care in Uganda. They have teamed up with FHSSA to offer a great new way to build awareness and donations around your Partnership through an Event-in-a-Box.

Okuyamba follows the journey of Rose

Kiwanuka, Uganda's first palliative care nurse, as she travels throughout the country, training, supporting and encouraging the nation's 120 palliative care professionals. This powerful documentary is a great tool to help build awareness of the need in Africa and how work is accomplished.

The Event-in-a-Box materials you will receive include the DVD of the film, Okuyamba, a How-To guide for hosting a screening, customized posters and self-mailer postcards, and template media requests.

"The Event-in-a-Box is a great new tool for our partners to increase community



awareness and raise needed support for their partnership," states, John Mastrojohn, FHSSA's Executive Director.

Want more information on how the Event-in-a-Box can help your FHSSA Partnership? Ready to host your own screening? Visit <http://www.okuyamba.org/>

African Hospices Can Now Benefit from the National Hospice Foundation's Run to Remember® Program

Ellen Green of Hosparus Inc. Raised Money for Shepherd's Hospice in Sierra Leone

Ellen Green, Senior Director of Counseling Services at Hosparus Inc., which serves Kentucky and Southern Indiana, was the first person to take advantage of a new opportunity to raise money for an African hospice through the National Hospice Foundation's Run to Remember® program. She ran the Carmel Marathon in Carmel, Indiana, on April 20, 2013. This was her first marathon.

Since 2009 Hosparus has partnered with Shepherd's Hospice in Sierra Leone. Green used the Carmel Marathon to raise funds to support their sister hospice a continent away. "I have run five half-marathons in the past five years and I decided I wanted to try a full one. I know our sister hospice in Sierra Leone has many needs. I thought raising money for Shepherd's Hospice would provide some additional motivation and inspiration for me as I continue my training," said Green.

Shepherd's Hospice is headquartered in Sierra Leone's capital city of Freetown and has a clinic in a rural part of the country. In February, they broke ground on a new 10-bed clinic and hope to have it built by the summer of 2014. Hosparus hopes to raise a total of \$15,000 to help furnish the new clinic with medical equipment. With a \$15,000 investment, Hosparus can work with the nonprofit Supplies Overseas to ship approximately \$150,000 - \$200,000 worth of equipment to the Shepherd's Hospice.

A policy change for 2013 at the National Hospice Foundation's Run to Remember program means that runners and walkers who are raising money for hospice care can now designate 50 percent of their proceeds to go to an African hospice. In the past, such designations were restricted to U.S. hospices.



Ellen Green of Hosparus in Kentucky is the first Run to Remember runner to raise money for an African FHSSA partner.

African hospices that are FHSSA partners can benefit directly from runners and walkers raising money through Run to Remember. "By opening up Run to Remember to FHSSA, we are adding an exciting, active way for FHSSA supporters to raise money for an African partner," says John Mastrojohn, executive director of both FHSSA and NHF.

Run to Remember is an easy way to raise money. All a runner (or walker) has to do is 1) register for a race (anywhere/any place) and then 2) sign up with Run to Remember to gain access to online fundraising tools. Hospices do not need to host a race. To learn more, visit www.fhssa.org/RTR or contact Jeremy Taglieri at 703-647-5172 or jtaglieri@fhssa.org

Another Partnership—Another Friendship



In March, a team of staff and volunteers from Samaritan Healthcare & Hospice of New Jersey visited their FHSSA partner, Kawempe Home Care in Kampala, Uganda. The team, which included a physician, two social workers, two nurses, a massage therapist and two volunteers, travelled 8,000 miles to see firsthand the impact that their FHSSA partnership has had. The visit had a significant impact on the visitors. Upon returning, Joanne Rosen commented, "We are more enthusiastic than ever about increasing our support for [Kawempe's] mission."

Every year FHSSA partners engage in exchanges just like this one. As the team from Samaritan discovered, such visits provide a unique opportunity to develop a partnership based on the goal of, "idea-sharing, professional exchanges, technical assistance, educational development and organization support."

If you are interested in learning more about how to become a FHSSA partner, please visit our website at www.fhssa.org or contact jtaglieri@fhssa.org.

Crowdfunding News

FHSSA Second Campaign Focuses on Nursing Scholarships

"Social fundraising" or "crowdfunding" is a powerful new tool that describes an effort by individuals who network and pool their resources to support a cause, or individual projects within a larger mission. In December, FHSSA started our first crowdfunding campaign, which focused on raising support for FHSSA's Conquering Pain project.

The current FHSSA campaign is called Make an Impact and can be viewed at <http://crowdfunding.fhssa.org/campaign/detail/974>. This \$10,000 campaign will provide scholarships to African nurses for post-graduate training in palliative care. Millions of people in Africa suffer in pain from terminal illnesses such as HIV/AIDS, but there are too few medical workers trained in palliative care and pain management to help them. This campaign will provide funding for up to five nurses to receive post-graduate training in palliative care service provision.

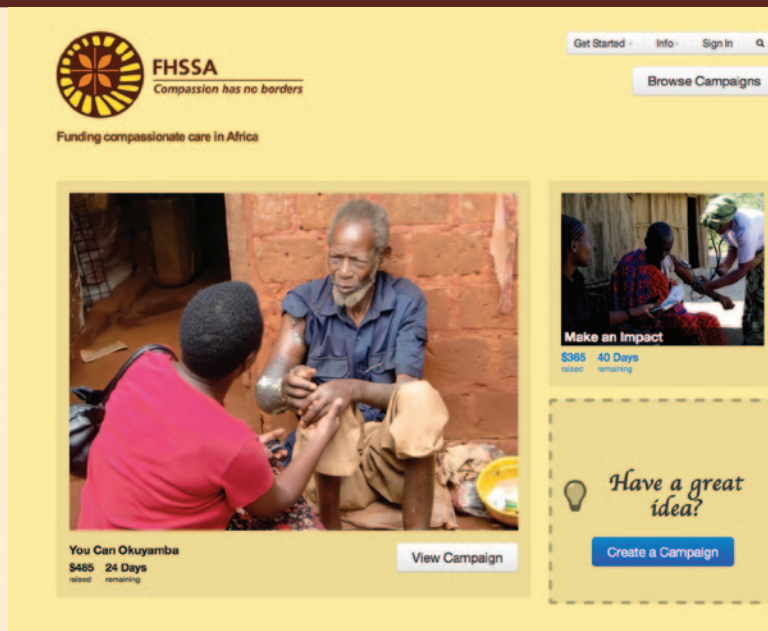
In Africa, nurses provide the majority of health care, making it essential to ensure that they are properly trained in palliative care. This scholarship pays it forward. One trained nurse in palliative care will educate and train additional workers and family members, resulting in a growing network of palliative care provision.

To help meet the demand for educated nurses, FHSSA and the African Palliative Care Association (APCA) created the African Palliative Care Nursing Scholarship Fund which provides scholarships for nurses to receive post-graduate palliative care training. In Africa, nurses are also a primary source for medical education and mentorship for students, patients, families, and community health workers. The impact of a nursing scholarship goes far beyond the education of the nurse, and results in an expanding network to continue to promote and provide essential pain relief to those suffering throughout the continent.

"Even one dollar can have an impact when you're working together to make a profound difference for people in Africa who are struggling with illness and pain," said John Mastrojohn, executive director of FHSSA. "Our crowdfunding site is a great way to donate, share among friends and family and know specifically how your contribution will be used

to make a difference." Visit crowdfunding.fhssa.org to learn more about this new tool and to see the current projects using crowdfunding.

Any U.S. FHSSA partner who wants to raise money for a specific project for their African partner can also take advantage of FHSSA's crowdfunding web platform. Thus far, FHSSA and our participating partners have raised over \$11,000. If you would like to learn more about how to set up your own crowdfunding campaign, contact Jeremy Taglieri at 703-647-5172 or jtaglieri@fhssa.org.



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



FHSSA

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