

PCAU PARTNERSHIP REPORT 2016 UPDATE



Dear Friends and Supporters,

If hope was a color it might be as lush and green as the landscape of Uganda. Since 2008, our partnership with the Palliative Care Association of Uganda (PCAU) has fostered hope for those in need of palliative care in Uganda, for the dedicated healthcare workers who provide that care and for the children in our Road to Hope program.

Some of the children in this program are featured in our latest documentary, *Road to Hope*. This film captures the challenges faced by children in Sub-Saharan Africa who cared for their dying parents. One of the biggest questions posed by their patients is, “who will care for my children when I die?” The Road to Hope fund was created to provide an education for some of these children. Thanks to the generous support of donors we are now able to send 44 children to school, providing them with food, supplies, school fees and uniforms.

Our partnership has been marked by a number of other successes – each year we add to these. You’ll find many of them described in this report. They wouldn’t be possible without the generous donors who support this relationship that spans half the globe. While there is still much to do to tackle the monumental task of bringing palliative care to a country with a population of 41 million and virtually no health care infrastructure in place, much has been accomplished in a short time. We tell the story of our partnership to provide a setting for the work still to be done.

Thank you for sharing the journey with us – and thank you for your support.



Mark Murray
President/CEO
Center for Hospice Care
& Hospice Foundation



Mike Wargo
Vice President/COO
Hospice Foundation



Rose Kiwanuka
Country Director
Palliative Care Association
of Uganda



The Road to Hope fund provides support for orphaned and at-risk child caregivers in Uganda.



Rose Kiwanuka and Mike Wargo review the partnership's progress in providing palliative care in each of Uganda's 112 districts.



Partnership Background & Goals

In 2008, Center for Hospice Care (CHC) applied to FHSSA (now Global Partners in Care) to become a partner hospice. While most American hospices were being assigned to a specific African hospice program, CHC was partnered with the Palliative Care Association of Uganda (PCAU), whose mission is “to promote and support affordable and culturally appropriate palliative care throughout Uganda.”

PCAU is a member organization for palliative care professionals, care providers and organizations. Its vision is “Palliative care for all in Uganda,” and supports and promotes the development of palliative care services in Uganda. Working within the national framework for palliative care set out in the National Health Sector Strategic Plan, PCAU is mandated with providing leadership and coordination in order to scale up palliative care education and services throughout Uganda. It does this in conjunction with the Ministry of Health, local partners, stakeholders and in partnership with regional and international development organizations.

Established in 1999 and registered as an NGO in 2003, PCAU has successfully supported the expansion of palliative care services in 93 out of 112 districts of Uganda. However, there are still a number of unmet needs. It is estimated that only 10% of the Ugandan population with palliative care needs can access these services, thus integration of palliative care services into the health system is essential to close this gap.

Our focus is providing support and resources to assist PCAU in reaching its strategic objectives. Ongoing communications and in-person visits help assure that our activities are aligned with

PCAU’s objectives and strengthen the personal relationships that are so crucial to the partnership’s success.

These strong, meaningful relationships between staff members at CHC/HF and PCAU are fostered through regular correspondence and Skype meetings as well as staff exchanges. We also support PCAU’s efforts to achieve long-term sustainability through technical/web, financial and operational assistance.

PCAU Strategic Objectives

- 1. Capacity Building:** to comprehensively integrate palliative care services in every district of Uganda through a system of training, mentorship and support supervision.
- 2. Advocacy:** to increase awareness, understanding and affect the necessary policies and procedural changes to achieve the overall goal in Uganda.
- 3. Information Gathering and Dissemination:** to be the central hub for data and information on palliative care service provision in Uganda by collecting, storing and regularly disseminating information to improve services.
- 4. Sustainability:** to establish a secure financial base through strong membership and partnerships ensuring permanency and relevance of PCAU, and the integration of palliative care services into the health systems.

These objectives are complementary and overlapping and work towards the sustainable integration of services, which are embedded within institutions, not dependent on individuals.

Palliative Care in Uganda

In 2013 (the most recent year for which records are available), 1.1 million people died of AIDS-related causes in Sub-Saharan Africa. Uganda faces enormous challenges in providing even the most basic palliative care. As noted earlier, only approximately 10% of Ugandans are currently able to access palliative care.

Like many African countries, there is little or no access to adequate pain medication, hospice and palliative care, in addition to already desperate situations of suffering, poverty, and isolation. The availability of healthcare in Uganda is very limited and the majority of Ugandans go an entire lifetime without ever seeing a physician. For those living in the rural areas of Uganda, there is one doctor for every 50,000 people. Consequently, nurses assume a major role in health care.

Once a Ugandan contracts cancer or other life-limiting illnesses, he or she is frequently left with little or no opportunity to pursue curative treatments. For example, there is only one radiation center for the treatment of cancer in the entire country. Those

fortunate enough to be able to travel to the capital city of Kampala for radiation treatment must deal with the fact that the machine is often down and that there are frequent, prolonged disruptions of electrical power. And currently, the machine is inoperable. Many Ugandans lack the financial resources or the means to travel at all. Consequently, the mortality rate, and corresponding need for palliative care, is very high. All of these facts help account for Uganda's low life expectancy of 52 years, and why half of the country's 41 million people are under the age of 15.

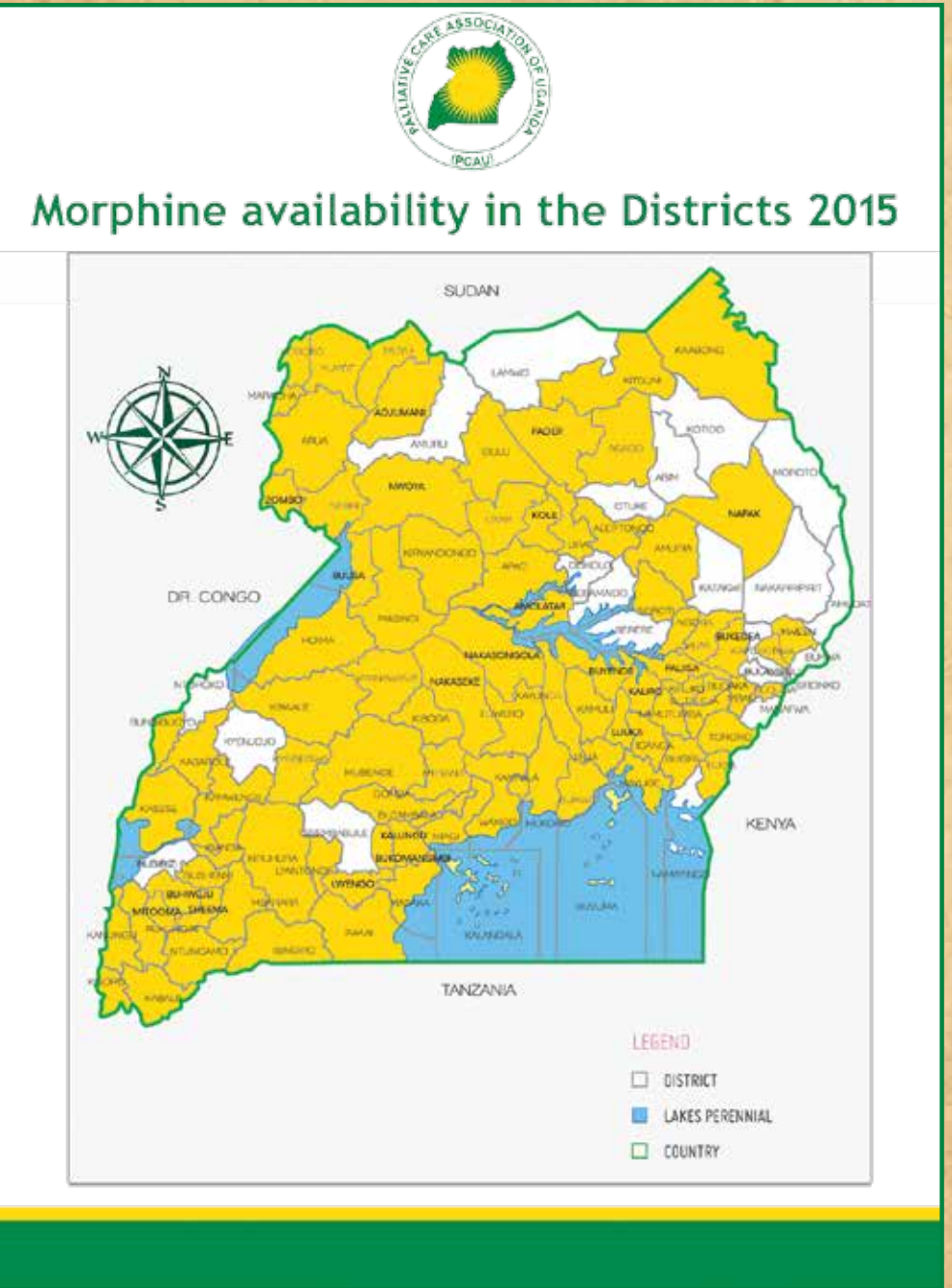
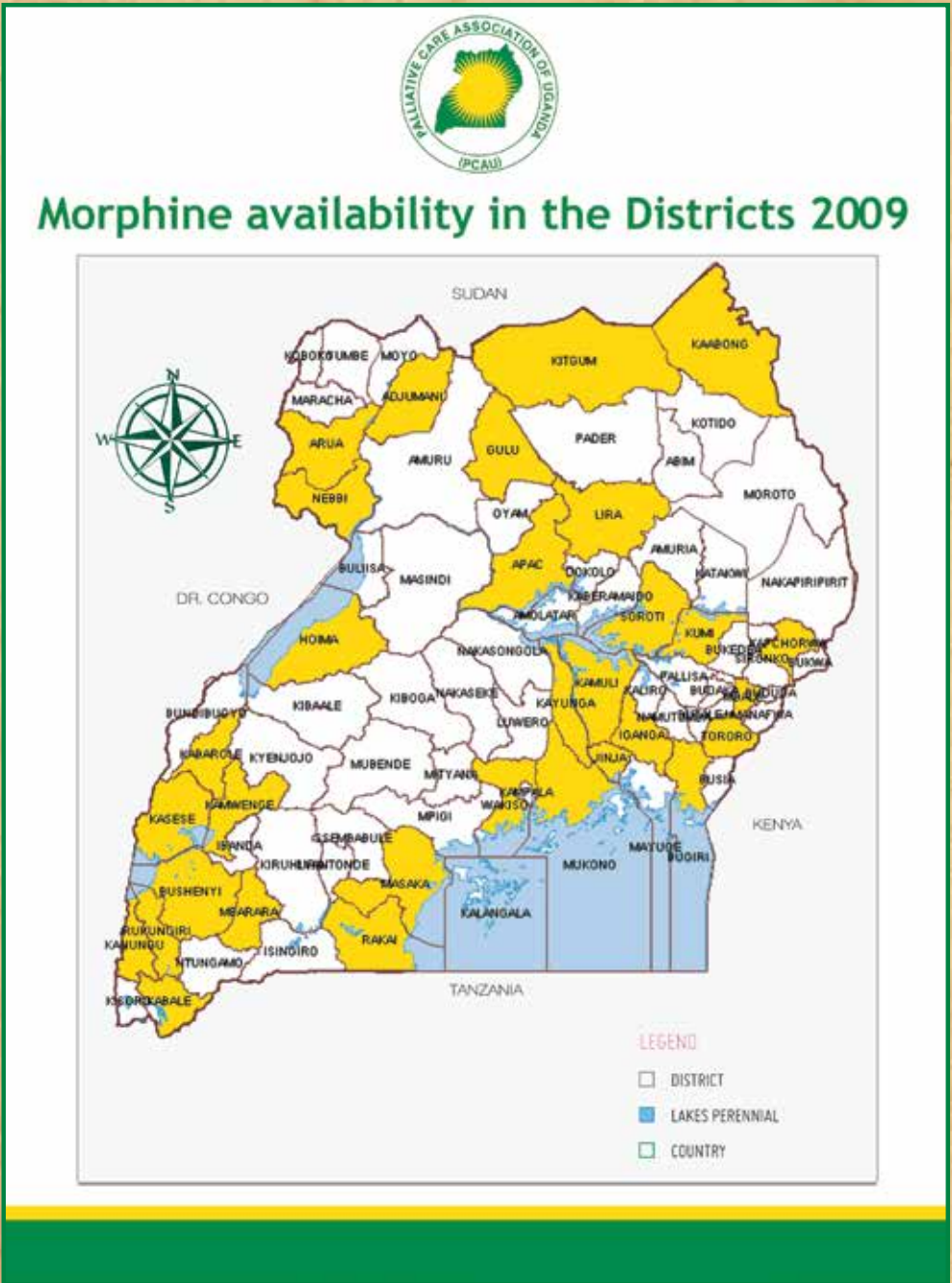
Yet, thanks in great part to the efforts of PCAU, Uganda was ranked second in the region of Africa/Middle East in the 2015 Quality of Death Index report published by The Economist Intelligence Unit. Uganda received a rating of 48.5, putting it behind only South Africa in its region. By way of comparison, the US received a rating of 80.8 while the highest-rated country, the UK, received a 93.9.



Center for Hospice Care/Hospice Foundation President/CEO Mark Murray visits a palliative care patient along with PCAU staff members on a recent visit.



Gaby Austgen, a master's student at the Eck Institute for Global Health, visited a number of patient care sites during her internship.



Collaborations

Many of the partnership's achievements would not have occurred without the help of other organizations. Faculty and students in departments, institutes and centers throughout the University of Notre Dame in particular have played key roles in advancing PCAU's strategic goals – and helped us define new ones.

Internships

The partnership has been able to facilitate palliative care and spiritual care internships in Uganda for Notre Dame students, with the support of the Kellogg Institute for International Studies, the Ford Family Program and the Center for Social Concerns.

Hanna O'Brien, a College of Science Pre-Professional Studies and Anthropology double major, was the first student to study in Uganda during the summer of 2010. She returned the following summer for another internship. Master of Divinity students Ben and Mary Ann Wilson also went to Uganda in the summer of 2011 to serve as spiritual care interns.

Brianna Kunycky, working at Notre Dame's Geospatial Analysis Laboratory under the direction of Dr. Dilkushi Pitts, created a new palliative care map that depicts the geographic deployment of palliative care workers throughout Uganda. Her work helped identify coverage gaps and aided in prioritizing those areas of the country that most needed certified palliative care workers.

In 2013, three Notre Dame students, Gaby Austgen, Anna Heffron and Emmie Mediate, interned in Uganda. Each student was paired with a PCAU member organization for his/her internship.



Anna, Gaby and Emmie with Rose Kiwanuka during their Ugandan internships.

Austgen, a master's student with the Eck Institute of Global Health, worked on improving PCAU's data collection and monitoring system by consolidating existing information into an easy-access database and preparing a framework for the next country-wide audit. Her project laid the groundwork for the mHealth pilot overseen by Brianna Wanless, detailed later in this report.

Emmie Mediate returned to Uganda for a second year in 2014 to work on quantitative and qualitative research to evaluate the effectiveness of international HIV/AIDS programs in sub-Saharan Africa. She also pursued her research in Sweden and the Netherlands, which resulted in a thesis titled, "Disabling Donor Demands: The Coercion of the International HIV/AIDS Agenda." In addition to this work, Mediate also conducted research on the President's

Emergency Plan for Aids Relief (PEPFAR) and mined perceptions of NGOs in Uganda. She was named a Rhodes Scholar in 2016 and will begin studying at Oxford University in October 2016.

The partnership has also been fortunate to have as interns Cliff Arnold and Graham Englert, who spent time at various PCAU member organizations in 2014.

Eck Institute for Global Health

As part of her program with the Eck Institute for Global Health, Brianna Wanless developed an mHealth pilot program in 2015 that uses mobile phones to track and update palliative care throughout the country. Palliative care practitioners will provide PCAU with vital statistics such as the number of patients being cared for at various member locations as well as track morphine supplies. Intern Brian Vetter also provided assistance for the program. Wanless presented a summary of the project at PCAU's 6th Biennial National Palliative Care Conference in August 2015. More than 400 palliative care delegates from around the world attended the conference, which was held in Kamapala, Uganda.

The project is now in Phase II and being expanded to additional palliative care facilities throughout the country. It is overseen by Eck faculty member Lacey Ahern. Master's student Katie Anderson will spend eight weeks in Uganda during the summer of 2016 to implement this phase.

The Eck Institute for Global Health has been integral in helping our partnership identify resources, both in the US and Uganda, that are able to further PCAU's strategic goals.



Brianna Wanless presents her mHealth project at the 6th Biennial National Palliative Care Conference.

Collaborations

Department of Film, Television, and Theatre

The short documentary film *Okuyamba* began as a way to increase awareness of the need for palliative care in developing countries like Uganda. It wouldn't have been possible without the assistance of Department of Film, Television, and Theatre faculty member Ted Mandell and students from the department – Jacob Griswold and Michelle Carlisle Lee – who served as assistant director and boom/camera operators.

Department alumni were also vital to the filming of the foundation's second documentary, *Road to Hope*. Collin Erker and Marty Flavin, both graduates of the program, handled sound and lighting and served as additional camera operators. See the sections about the *Road to Hope* film and fund for more information.

Mendoza School of Business at the University of Notre Dame/Executive MBA Program

"Business as Usual," a team of students enrolled in the Executive MBA program, made Uganda's morphine supply chain its case project in 2015. The team consisted of Andrew Feichter, Justin Remmelts, Ruth Riley, Katie Sabo, Benoit Siniora and Neal Wozniak. The project analyzed morphine distribution throughout the country, advanced strategies to improve the procurement and distribution process and determined how to increase awareness and advocacy for palliative care.



The film crew from the Okuyamba documentary. L to R: Mike Wargo, Michelle Carlisle Lee, Mike Lee, Mugisha "Owen" Muhammed, Jacob Griswold.



Road to Hope film crew with George, one of the stars of the film. L to R: Denis Kidde, George Bazaire, Mike Wargo, Collin Erker, Timothy Wolfer, Marty Flavin.

In June of 2015, the team traveled to Uganda to meet with PCAU, the Ministry of Health and other key stakeholders. A summary of their findings and recommendations was delivered at the 6th Biennial National Palliative Care Conference in August. PCAU, in conjunction with the Ministry of Health, is implementing many of the team's recommendations.



The Executive MBA Program students from Notre Dame with some of their Ugandan partners.

Friends of Uganda Network (FUN)

FUN – the Friends of Uganda Network – is an unofficial group of St. Joseph County, Indiana organizations and individuals that meets regularly to share updates about work being done to improve the quality of living in Uganda. While many of the initiatives are not directly related to palliative care delivery, a number of connections to non-governmental organizations, religious and educational entities in Uganda have enhanced the partnership's ability to meet PCAU's goals.



Intern Hannah O'Brien with a child in Uganda.

Road to Hope

No Parents. No Future. No Hope.

When parents are stricken with life-limiting illnesses in Sub-Saharan Africa, their children often become their primary caregivers. With no other source of income, these children quit school to earn whatever living can be found, while still caring for the dying parent. But what happens to these children once the parent dies?

With no one to care for and no one to care for them, they have few options. If they're lucky, small children may be taken in by an orphanage or absorbed into the village. For others, fate may lead them down a different path. Teenage girls may be married off while their brothers take to living on the streets, begging and stealing in order to survive.

Whatever their ultimate fate, they all go searching – searching for hope. Hoping they'll see the next meal and be able to walk the next mile in search of a better life.

Filmed over a two-year period in Uganda, Kenya and South Sudan, the *Road to Hope* documentary examines the lives of three of these children as well as those who have emerged to shepherd them along the way.

Timothy Wolfer, of Wolfer Productions, served as Director of Photography. The film crew included Collin Erker and Marty Flavin. Denis Kidde, Hospice Foundation's International Program Coordinator, accompanied the crew as a consultant.



Joining the crew in Africa was actress and hospice advocate Torrey DeVitto. DeVitto is best known for her work in primetime network television shows such as *Chicago Med*, *Army Wives*, *Pretty Little Liars* and *The Vampire Diaries*, but her passion for raising awareness of hospice and care at the end of life is evident in her life. Since 2011 DeVitto has worked with NHPCO and the National Hospice Foundation as their first official Hospice Ambassador.

Hospice Foundation Vice President/COO, Mike Wargo, produced and directed the film. It follows on the heels of the foundation's first documentary, *Okuyamba*, which followed palliative care workers caring for patients dying deep in the villages of Uganda. *Okuyamba* was an official selection at a number of international film festivals and competitions, including The Indie Fest and Accolade Competition and received both a Best Shorts Award and Prestige Award in 2012. It was also 1st Runner-Up for Best Documentary Film at the 2012 Vegas CineFest and won a Bronze Telly Award for Social Responsibility. In addition, *Okuyamba* earned the highly coveted Zachary Morfogen Art of Caring Award from the National Hospice and Palliative Care Organization (NHPCO) in 2012.

Road to Hope is now on the film festival circuit and has garnered a number of awards including:



The *Road to Hope* documentary shares the stories of a number of child caregivers including George Bazaire (top left), Crispus Asasira (bottom left) and Christina (shown with her mother, Priscah).

Fundraising Initiatives

Okuyamba Fest

Each October, in honor of World Hospice and Palliative Care Day, CHC/HF hosts *Okuyamba Fest* to celebrate its partnership with PCAU, help increase awareness of the need for palliative care throughout the world and raise funds for PCAU.

The event, which features international food and beverage as well as a silent auction of Ugandan arts and craft items, began in 2012. Proceeds from the event have benefitted the PCAU building and general fund as well as the Road to Hope fund.

Brandi Milloy, TODAY Tastemaker and POPSUGAR Lifestyle TV Host and Producer, was the event keynote speaker in 2014. She discussed her volunteer work with PCAU in 2013 and her work with some of the children involved in the Road to Hope program.

Road to Hope Fund

The three child caregivers featured in the *Road to Hope* documentary represent the millions of child caregivers in Uganda. Years of war and the HIV/AIDS epidemic have created child-headed households throughout the country. While caring for their dying parents – and after they die – these children often have no access to formal education. With no breadwinner to support them, they often are forced to drop out of school and look for casual jobs such as selling ground nuts on the streets in urban areas or begging for money in order to survive.



Top: TV personality Brandi Milloy shares stories with Okuyamba Fest attendees in 2014.

Bottom: PCAU hosts a yearly camp for children in the Road to Hope program, which allows them to enjoy a fun-filled weekend in Kampala with others who have similar life experiences.

George Bazaire is one example. In the US, five-year-olds go to kindergarten, learn to read and begin their academic careers. In the village of Kakumiro, Uganda, five-year-old George cared for his dying father in their one-room mud home. When his father died he went to live with his mother, who had abandoned him years before. She was unable to care for basic needs and education.

George now attends school regularly and his basic needs of uniforms, school fees, room and board and supplies are covered by his Road to Hope sponsor. His progress is monitored on a regular basis by PCAU staff members; he will continue to receive support and encouragement by those associated with the program – on an official basis through his 18th year and unofficially beyond that.

Employee Giving

The Uganda Impact Fund, which is supported through payroll deductions from CHC and HF employees, is another important aspect of our partnership. The fund was established following Rose's initial visit to CHC in 2008 to allow employees to invest in PCAU's success. This support has enabled PCAU to establish its own permanent office location as well as provide funding for palliative care initiatives such as palliative care scholarships for nurses and clinical officers.

Through the end of 2015, employees have given \$26,648 to benefit PCAU. An average of 40 employees each year have participated in the program since its inception.



CHC employee Holly Farmer was selected to attend PCAU's 6th Biennial Conference in 2015. While in Uganda she met with one of the children sponsored by her family, Mark Kalema.

Future Goals

Turn Uganda Yellow

PCAU has successfully supported the roll out of palliative care services in 93 of Uganda's 112 districts. However, there is still a great, unmet need to provide skilled, compassionate care.

With the support of CHC/HF and others, PCAU's goal is to "Turn Uganda Yellow," indicating that palliative care services are available through a specially trained health care worker able to prescribe morphine, somewhere in each district.

CHC/HF has helped support this initiative through its sponsorship of scholarships in Hospice Africa Uganda's Diploma in Clinical Palliative Care program. This course allows clinical officers and nurses to prescribe morphine and provide palliative care. It combines theoretical course work with intense field training. Those who complete the course then return to their communities to provide these services. Through the end of 2015, CHC/HF had sponsored 34 students in the program.



Recent graduates of the Hospice Africa Uganda Diploma in Clinical Palliative Care program will join PCAU in helping make palliative care accessible to all in Uganda.

mHealth Initiative

The objective of this initiative is to strengthen palliative care surveillance throughout Uganda, which will allow PCUA to share accurate, timely information with stakeholders. Ultimately this will help lead to better delivery of palliative care service, enhanced communication with palliative care providers and allow the monitoring of morphine supply and use. Initiated by the Eck Institute for Global Health, PCAU and CHC/HF, the project has grown to include Notre Dame's Office of Information Technologies and Center for Social Research as well as Uganda Martyrs University. The pilot program, which tested hardware, software and content at four sites in Uganda was successfully completed in 2015. Phase II began in the fall of that year and will continue through 2016. This phase will add six more sites to the project and allow the partners to continue testing. Phase III will scale-up the project, eventually rolling it out to each of the country's licensed morphine prescribers.

Sustainability

Assisting PCAU in identifying and implementing programs that allow it to become sustainable has been one of the primary goals of the partnership since its inception. PCAU has been extremely successful in strengthening its organization and that of its member organizations, having grown from just one to 13 staff members. Since the partnership began, PCAU has moved from a borrowed office in the back of the African Palliative Care Association to a rental office to its own office, just off Entebbe Road which it now owns free and clear.

PCAU continues to move toward achieving the goals outlined in its strategic plan with the overarching goal of scaling-up palliative care service provision within the Ugandan healthcare system that will ultimately make palliative care accessible to the country's 41 million people. To accomplish this goal, the organization will consolidate and build upon what has already been achieved in terms of policy, morphine availability, training and implementation.

To achieve this, PCAU needs to ensure its own sustainability, which requires the acquisition of stable and permanent funding. Consequently, one of the four key objectives of PCAU's strategic plan is to achieve sustainability within the current funding context. This will require additional donor seed funding in order to implement many of its initiatives, particularly in the area of capacity building.

Many of our future initiatives will be in the areas of staff development, fundraising, communications, membership development, clinical and medical support, technical support and advocacy in the U.S., Uganda and around the world.

Staff Exchange Program

In order to support PCAU's ability to provide high-quality, continuing professional education as well as to promote the ongoing partnership and exchange of ideas between the two organizations, the Hospice Foundation facilitates staff participation opportunities for CHC/HF employees.

In 2013 Karen Smith-Taljaard, a CHC social worker, and Bridget Hoch, a CHC spiritual care counselor were invited to present at the 5th Biennial Conference in Uganda. Holly Farmer, Bereavement

During their 2015 visit to Uganda, some members of the CHC/HF team were able to visit Kawempe Home Care, a PCAU member organization.



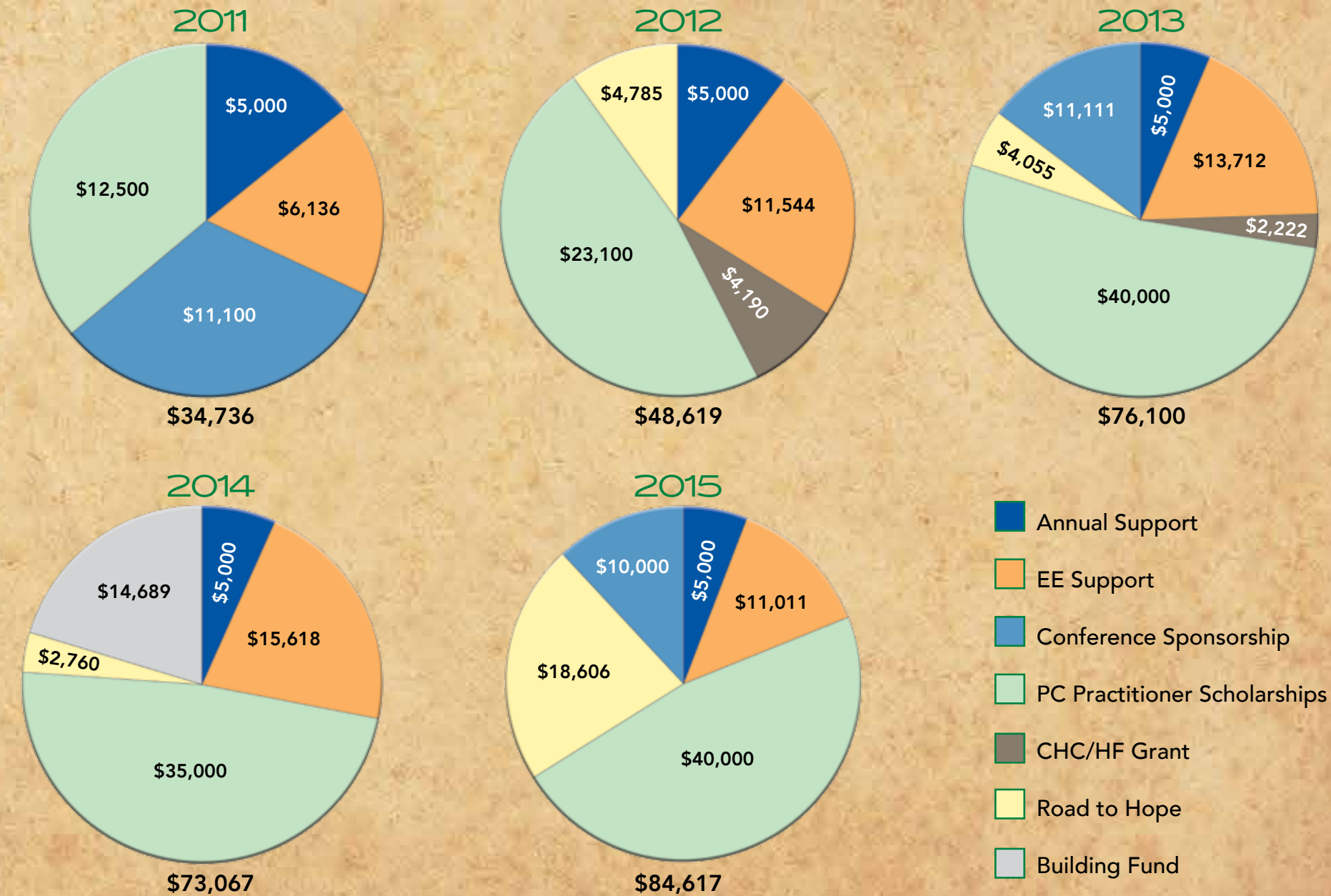
Coordinator for CHC's Life Transition Center, and Karen Hudson, a CHC nurse, were presenters at the 6th Biennial Conference.

Hudson's presentation, titled "Children Are Not Little Adults," focused on the need to provide child-centric holistic palliative care programs. Farmer's presentation had a similar theme, "Children Grieve Too: Recognizing and Supporting Grieving Children."

In addition to their poster presentations, Farmer and Hudson spent the following week working alongside their Ugandan counterparts. They also visited children who are part of the Road to Hope fund. In fact, Farmer's family sponsors a child in the program and she was able to visit him while in Uganda. She said, "Mark was happy to show me his classroom and I have photos of him in his seat, outside his school building and at his bunk bed (he has a top bunk). As we were walking out of the bunk room, he asked me when he would visit me in America. I was so touched by this and told him I hope it happens – I didn't know when, but I hoped it would be sooner rather than later."

Financials

Each pie chart below represents the total support, through both donations and grants, and other forms of support to PCAU for individual years from 2011 to 2015.



PCAU Donors

The generosity of PCAU donors seems to know no limits. They have made it possible for 44 children to attend school on the road to a better life. They have assisted PCAU in securing a permanent office location. They have helped fund efforts to make palliative care services available throughout Uganda. Without them, few of the partnership's initiatives would be possible.

Special thanks go to Torrey DeVitto, Brant Daugherty, Chris Evans, Ian Harding, Arielle Kebbel, Bethany Joy Lenz, Lindsey McKeon, Brittany Snow, Daphne Zuniga, Todd Krim, Brandi Milloy,

Christopher Blanchard and the staff at MTM, Chris Pan, Hope So Bright Foundation, Akvinta Vodka, and Magic Hat Brewing Company, Pia Mia and Trevor Jackson for putting together a Hollywood Road to Hope charity event at Bootsy Bellows, which raised more than \$24,800 for the Road to Hope fund.

In addition, our heartfelt thanks go to Torrey and Stevie Nicks for making possible a crowdfunding program that featured a meet/greet with Torrey and Stevie as well as two tickets to a San Diego Fleetwood Mac concert that raised more than \$13,000 for the Road to Hope children.



Top Left: The hosting committee for the 2014 Road to Hope fundraiser held in Hollywood, CA.

Left: Stevie Nicks (second from right) and Torrey DeVitto (left) with Brian Townley (right), who was the winning bidder of tickets from a crowdfunding event.

Above: Guests at the annual Okuyamba Fest chat while looking at some of the many silent auction items available for bidding.

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