

## 10 YEARS OF PARTNERSHIP









#### Dear Friends and Supporters,

Little did we know when our partnership began the impact our work would have. Thanks to those who have supported our partnership, thousands of people in need of palliative care in Uganda now have access to skilled, compassionate care.

This has been accomplished by work on many fronts, with many collaborators. The number of nurses and clinical officers who are able to prescribe morphine in rural districts has increased because of the partnership's support of the Diploma in Clinical Palliative Care program at Hospice Africa Uganda. Many collaborators, including the University of Notre Dame and the Uganda Ministry of Health have assisted in the mHealth program, which strengthens palliative care surveillance – including monitoring morphine supplies – throughout the country. We have produced two documentaries to raise awareness about the need for palliative care in low-resource settings and the plight of orphaned child caregivers.

You'll find these successes, and many others, described in this report. They wouldn't be possible without the generous donors who support this trans-Atlantic relationship. We tell the story of our partnership to provide a context for the work still to be done to make PCAU's vision of "Palliative care for all in need in Uganda" a reality. While there is still much needed to bring palliative care to a country with a population of 41 million and a stretched health care infrastructure, much has been accomplished in this decades-long journey. Thank you for your support and for walking along side us. We could not have come this far without you!







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



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**Mike Wargo** Vice President/COO Hospice Foundation



Rose Kiwanuka

Rose Kiwanuka
Country Director
Palliative Care Association
of Uganda







### Celebrating 10 Years of Partnership

exchange visits



years of Road to Hope sponsorships



PCAU staff members and documentaries

CHC employees have visited PCAU

internship collaborations



conferences sponsored

years of sponsoring DCPC students



years of PCAU in their own office



successful partnership

#### Why Palliative Care?

Palliative care provides relief from pain and symptoms resulting from life-limiting illness and is recognized as a human right by the World Health Organization (WHO). In low-resource settings, like Uganda, access to preventative and curative healthcare is limited. Many people don't see a physician. According to 2015 WHO statistics, there is one physician for every 11,000 Ugandans. Consequently, nurses assume a major role in providing health care, particularly in palliative care.

## 1:11,000

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. Consequently, the mortality rate and corresponding need for palliative care is very high.

Yet, thanks in great part to the efforts of PCAU, Uganda was ranked third 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 47.8, putting it behind only South Africa in Africa.

By comparison, the US ranks ninth worldwide with an 80.8 index.

# ISRAEL SOUTH AFRICA UGANDA 47.8

#### **Turning Uganda**

Middle East region

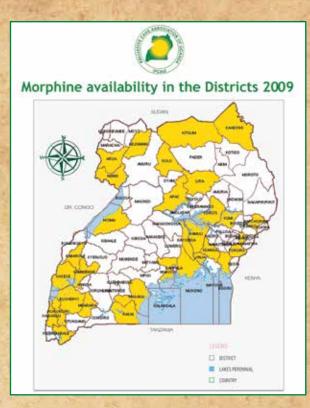
**UGANDA RANKS** 

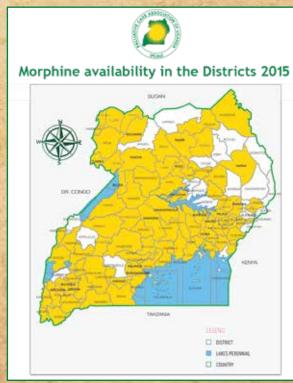
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in 2018 Quality of Death

Index report in Africa/

In the last 10 years, PCAU has successfully supported the expansion of palliative care services from 34 to 96 out of 121 districts of Uganda. Access to trained providers and morphine have greatly increased. However, there are still a number of unmet needs. It is estimated that only 11% 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.





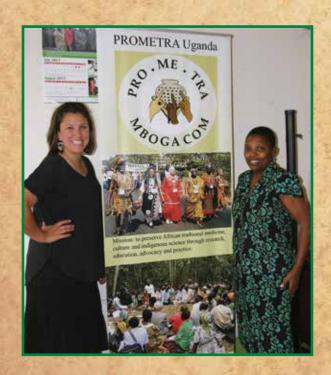
#### Palliative Care in "The Pearl of Africa"

Uganda was the first country in the world to allow nurses trained in palliative care provision to prescribe morphine. The government, in partnership with Hospice Africa Uganda, also provides oral morphine at no charge to hospices, clinics and hospitals that offer palliative care and have a registered palliative care provider on staff.

#### **About PCAU**

- Established in 1999 and registered as an NGO in 2003
- A member organization for palliative care professionals, care providers and organizations
- Vision: "Palliative care for all in need in Uganda"
- Mission: "To accelerate the integration of palliative care in the Uganda health care system through capacity building, advocacy, research and resource mobilization."





"To get the perspective of the PCAU staff and see their successes and barriers allowed me to see the global need for our work. Compassionate end-of-life care should be accessible to all, and knowing that many are still without such care has stirred a desire to be an advocate for all people, worldwide. It was powerful to be able to encourage each other in the work we do."

Kristiana Donahue CHC Volunteer Recruitment Coordinator

## Partnership History

In 2008, Center for Hospice Care (CHC) applied to be matched with a partner in a low-resouce setting through Foundation for Hospices in Sub-Saharan Africa (FHSSA), now Global Partners in Care. While most American hospices were being assigned to a specific African hospice program, CHC was partnered with the Palliative Care Association of Uganda (PCAU), the national association for palliative care providers throughout the country. In essence, CHC was partnered with the entire country of Uganda.

PCAU is a civil society organization established to support and promote the development of palliative care and palliative care providers 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.

The partnership's quantifiable successes over the past decade are documented in this report: acquiring an office building, providing scholarships for nurses and clinical officers to train in palliative care, implementing an mHealth surveillance system, providing tuition for orphaned child caregivers and hosting/sponsoring a bi-annual conference. Other impacts of the partnership are more difficult to measure – but may be even more valuable. These include the meaningful relationships that have grown between members of both organizations and the growing awareness of the need for palliative care because of our documentary films and internship program. We can count the number of students who are receiving an education because of the Road to Hope program but have no way to capture the difference this will make in their lives. We just know that it exists.





## Partnership Goals

PCAU's most recent five-year strategic plan covers the years of 2017-2021. The focus of the partnership is to provide 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 crucial to the partnership's success.

These strong, meaningful relationships between staff members at CHC/HF and PCAU are fostered through regular videoconference meetings and correspondence 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 2017-2021

- **1. Capacity Building** that is directed towards integrating palliative care services in every district of Uganda by 2021 through a system of focused training, mentorship and support supervision.
- **2.** Advocacy and Awareness Creation aimed at increasing the awareness and understanding of palliative care issues among stakeholders and thus leading to a supportive environment for the providers and the services.
- **3. Palliative Care Research and Information** aimed at making PCAU a hub of palliative care research and information by undertaking palliative care research and/or hosting relevant research and leading the collection, storing, and analysis of data and by regularly disseminating information to improve palliative care services.
- 4. Governance and Financial Resource Mobilization for Palliative Care: PCAU hopes to strengthen its governance and resource mobilization capacity and establish adequate financing and related resources for scaling up and integrating palliative care in Uganda and enhancing the sustainability and relevancy of PCAU.





## Diploma in Clinical Palliative Care

Healthcare providers who are specially trained in palliative care and licensed to prescribe morphine are essential to the provision of palliative care in remote areas of Uganda. Center for Hospice Care and Hospice Foundation (CHC/HF) have helped support this initiative through its sponsorship of scholarships in Hospice Africa Uganda's Diploma in Clinical Palliative Care (DCPC) program. This one-year course equips clinical officers and nurses with the skill set needed to prescribe morphine and provide palliative care. Those who complete the course then return to their communities to provide these critically needed services. Through 2018, CHC/HF had sponsored 62 students in the program.







## Sharing Our Experiences

Regardless of the setting, the provision of palliative care relies on the same basic aspects – culturally appropriate care delivered by skilled, compassionate staff members. Our partnership recognizes the importance of this and has made the facilitation of staff exchange visits and

sponsorship of PCAU's biennial conference priorities. In the last 10 years, nine Center for Hospice Care staff members have been part of the staff exchange visits/conference presentations. PCAU staff members have visited to US on alternating years.

#### PCAU Staff



Rose Kiwanuka
Country Coordinator
(Shown here with CHC staff members Dr. Greg Gifford and Daniel Kassner)



Mark Mwesiga Programs Manager



Cynthia Kabagambe ICT & Data Quality Officer

"The greatest take away was the contentment and resiliency of the Ugandan spirit. I went believing I could offer their program insight and suggestions... instead they taught me more than I could have ever imagined. I was more than fortunate to have had the experience and share in this partnership."

Karen Hudson CHC Patient Care Coordinator



## Staff Exchanges

#### **CHC Staff**



Karen Smith-Taljaard Social Worker



Bridget Hoch Chaplain



**Cyndy Searfoss**Director of Collaborative
Partnerships, Hospice Foundation



Mark Murray President/CEO



**Denis Kidde**International Program Coordinator,
Hospice Foundation



Mike Wargo
Chief Operating Officer,
Hospice Foundation



Lacey Ahern Manager of International Programs

#### 2013

Karen Smith-Taljaard, a CHC social worker, and Bridget Hoch, a CHC spiritual care counselor, presented at the 5th Biennial Conference in Uganda.

#### 2015

President/CEO Mark Murray chaired a plenary session at the 6th Biennial Conference. Holly Farmer, Bereavement Coordinator for CHC's Life Transition Center, and Karen Hudson, a CHC nurse at the time, also presented at the conference.

#### 2017

Holly Farmer was invited to participate in a panel discussion at the joint PCAU – Uganda Cancer Institute conference. Kristiana Donahue, CHC Volunteer Recruitment Coordinator, gave a presentation on recruiting and engaging volunteers. Hospice Foundation employees Denis Kidde, Cyndy Searfoss, Lacey Ahern and Mike Wargo held a workshop focusing on partnership development.



Bereavement Coordinator

**Holly Farmer** 

Kristiana Donahue Volunteer Recruitment Coordinator

## Connecting Resources, Creating Impact

Without the help of many collaborators, our partnership would not have been able to accomplish so much.

#### Internships

The partnership has facilitated undergraduate and graduate level internships and student experiences in Uganda for students from Notre Dame and Holy Cross College.



















Because Experience Matters.



"A highlight of my time with PCAU was getting to work with several stakeholders, all pushing to expand palliative care service in the country. In partnering with the Ministry of Health, civil society organizations, members of the police, and physicians, I saw firsthand how PCAU plays an important coordinating role. It's amazing that the organization, under Rose's passionate direction, is able to bring together so many different actors around a shared mission."

Emily Mediate Rhodes Scholar, Oxford University

#### mHealth Pilot Program

Working with Lacey Ahern, faculty advisor with the Eck Institute for Global Health, Brianna Wanlass developed an mHealth pilot program in 2015 that uses mobile phones to track palliative care throughout the country. 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. Work on the mHealth program was continued by Katie Anderson, Lily Ramos Drale, Kaitlyn Syler and Yutong Liu.

#### Tracking Morphine Supplies

"Business as Usual," a team of students enrolled in the Mendoza School of Business' Executive MBA program, made Uganda's morphine supply chain its case project in 2015. 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.



#### Notre Dame Student Interns

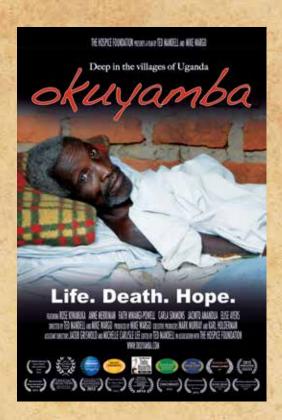
STUDENT	YEAR	AFFILIATION
Hanna O'Brien	2010, '11	Kellogg Institute for International Studies
Jacob Griswold	2010	School of Film, Television & Theatre
Michelle Carlisle Lee	2010	School of Film, Television & Theatre
Ben Wilson	2011	Master of Divinity Program
Mary Ann Wilson	2011	Master of Divinity Program
Brianna Kunycky	2011	Glynn Honors Program
Emily Mediate	2013, '14, '18*	Kellogg Institute for International Studies
Anna Heffron	2013	Kellogg Institute for International Studies
Collin Erker	2013	School of Film, Television & Theatre
Gaby Austgen	2013	Eck Institute for Global Health
Marty Flavin	2013	School of Film, Television & Theatre
Anne Sescleifer	2014	Kellogg Institute for International Studies
Cliff Arnold	2014	Kellogg Institute for International Studies
Graham Englert	2014	Jordan College of Science
Andrew Feichter	2015	Mendoza College of Business Executive MBA Program
Ben Siniroa	2015	Mendoza College of Business Executive MBA Program
Justin Remmelts	2015	Mendoza College of Business Executive MBA Program
Neal Wozniak	2015	Mendoza College of Business Executive MBA Program
Ruth Riley	2015	Mendoza College of Business Executive MBA Program
Katie Sabo	2015	Mendoza College of Business Executive MBA Program
Bri Wanlass	2015	Eck Institute for Global Health
Brian Vetter	2015	Kellogg Institute for International Studies
Yutong Liu	2016, '18	Hesburgh-Yusko Scholars Program
Katie Anderson	2016	Eck Institute for Global Health/USAID Fellow
Lilian Ramos Drale	2017	Eck Institute for Global Health/USAID Fellow
Kaitlyn Syler	2018	Eck Institute for Global Health

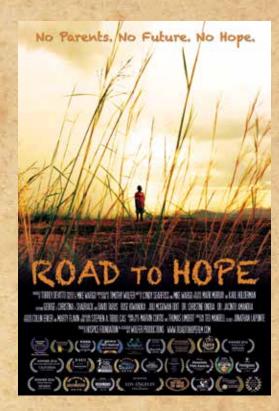
<sup>\*</sup> As a Rhodes Scholar/Master of Public Policy student at Oxford University

#### Department of Film, Television, and Theatre

The short documentary film Okuyamba was produced as a way to increase awareness of the need for palliative care in low-resource settings such as 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, served as additional camera operators and assistant editors







The film crew from the Okuyama 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.



## Community Engagement

#### Friends of Uganda Network

The Friends of Uganda Network (FUN) is a group of organizations and individuals who meet over lunch on a regular basis to share information about work they're doing in Uganda. The loosely afilliated group is made up of non-profit/non-governmental organizations and individuals who support work done by these types of organizations in Uganda. The purpose is to look for joint opportunities to further good work being done in the country and share information, best practices, and lessons learned.



"The partnership offers a picture of the needs of others in today's world, especially in Uganda, and an opportunity to help to meet these needs."

Roberta Spencer Volunteer

#### **Volunteer Visits**

Retired CHC Director of Support Services Roberta Spencer has been a volunteer liaison for the partnership since its inception. During her frequent visits to Uganda, she has helped facilitate the partnership's strategic initiatives and provided on-the-ground support for many of our ongoing projects. She has given workshops to partner palliative care organizations throughout the country, met with health officials regarding palliative care support, provided technical and logistical support to PCAU at its facility and helped administer grants for the Road to Hope fund. She played a crucial role in establishing the Road to Hope Camp and the **Empowerment Retreat for older Road to Hope** students and works with PCAU staff to put on the yearly camp/retreat.

Roberta shares her experiences in Uganda by blogging on the Hospice Foundation's website (foundationforhospice.org/uganda-trips).



## Road to Hope Program

#### Hope for the Future

In Uganda, like much of Sub-Saharan Africa, when a parent is struck with a life-threatening disease, many times a child is forced to become the primary caregiver. With no source of income, the child quits school to earn whatever living can be found while caring for his or her dying parent. PCAU meets many, many child caregivers through its work with member organizations. Healthcare workers identify vulnerable child caregivers, particularly those who have lost one or both parents, for the Road to Hope program. This program provides financial and social support, covering school fees, the cost of uniforms and food as well as regular visits by a social worker to assess the child's progress and provide social support.











"My family supports two children on the Road to Hope program and I was able to visit them. The time with Mark and Noeline is precious and the gratitude shared by them and their granny is palpable. Granny's daughter, Mark and Noeline's mom, died from an illness and providing financial support allows them to continue their education, something they would not be able to afford on their own. Providing finances for their education is so fulfilling and I am grateful for the opportunity to support them."

Holly Farmer Road to Hope Supporter

## DOCUMENTARIES

# okuyamba

The foundation's first documentary, *Okuyamba*, the Lugandan word meaning "to help," followed palliative care workers caring for patients dying deep in the villages of Uganda. Co-directed by Mike Wargo and the University of Notre Dame's Ted Mandel, the film was an official selection at a number of international film festivals and competitions. It also earned the highly coveted Zachary Morfogen Art of Caring Award from the National Hospice and Palliative Care Organization (NHPCO) in 2012. It continues to be used to raise awareness of the need for palliative care in low-resource settings. Fellow CHC/HF staff members Mark Murray and Karl Holderman were executive producers on the project; Cyndy Searfoss and Jim Wiskotoni worked on promotional pieces for this film, as well as HF's second documentary, *Road to Hope*.







# ROAD TO HOPE

Filmed over a two-year period in Uganda, Kenya and South Sudan, the *Road to Hope* documentary examines the lives of three children who cared for their dying parents as well as the people who emerged to shepherd them along the way.

Timothy Wolfer, of Wolfer Productions, served as the film's editor and 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.

Actress and hospice advocate Torrey DeVitto, best known for her work in primetime network television shows such as Chicago Med, Army Wives, Pretty Little Liars and The Vampire Diaries, joined the crew in Africa and served as narrator for the film.











## A Permanent Home for PCAU

One of the partnerships early strategic priorities was to find sustainable office space for PCAU's headquarters. In its infancy, PCAU volunteers and staff members worked from the offices of both Hospice Africa Uganda and the African Palliative Care Association. The need for a permanent, sustainable office soon became apparent.

In 2012, proceeds from CHC/HF's inaugural Okuyamba Fest, were directed toward purchasing a facility. CHC staff members also provided support, individually and through the employee-funded Uganda Impact Fund.

PCAU's long awaited dream of having a home was realized in 2013, after receiving additional support from the Princess Diana Legacy fund.











## Global Partnership Award

There is no finer recognition than that of our peers for a job well done. Our partnership was awarded the FHSSA Global Partnership award in 2013 in recognition of the outstanding efforts that went above and beyond the expectations of a partnership. Our selection was based on creativity in fundraising, partner collaboration, staff contribution and commitment, and community outreach and involvement. Along with this recognition, the award came with a cash contribution to PCAU.

"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 healthcare workers who work tirelessly with limited resources to provide that care," said John Mastrojohn, executive director of FHSSA.







## PCAU DONORS

The generosity of PCAU donors seems to know no limits. They have made it possible for 62 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.

#### Okuvamba Fest

Since 2012 CHC/HF has hosted an evening of international food and beverages called "Okuyamba Fest" to celebrate its partnership with PCAU. The evening also serves to increase awareness of the need for palliative care throughout the world and helps raise funds for PCAU through a silent auction of Ugandan art and craft items.



















#### Hooray for Hollywood

The Road to Hope program has benefitted greatly from the generosity of people who have helped us raise awareness – and funds – for the program. 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 in 2013, which raised more than \$24,800 for the Road to Hope fund.

#### Stevie Nicks Meet and Greet

In addition, our heartfelt thanks go to Torrey DeVitto and Stevie Nicks for making possible a crowdfunding program that featured a meet/greet with Torrey and Stevie as well as four tickets to a San Diego Fleetwood Mac concert that raised more than \$13,000 for the Road to Hope children in 2014.













## PCAU Donors

#### Road to Hope Fund

Currently, 57 children are enrolled in the Road to Hope program. This program provides financial and social support, covering school fees, the cost of uniforms and food as well as regular visits by a social worker to assess the child's progress and provide social support. The program also hosts a yearly camp for the children to gather for fun and enrichment activities.

#### **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 2009 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 2018, employees have given nearly \$120,000 via payroll deduction. An average of 40 employees each year have participated in the program since its inception.

"I give because my small donation can make a huge impact on the life of someone in need -a patient, child, or healthcare professional."

**Becky Kizer Executive Office Manager** 

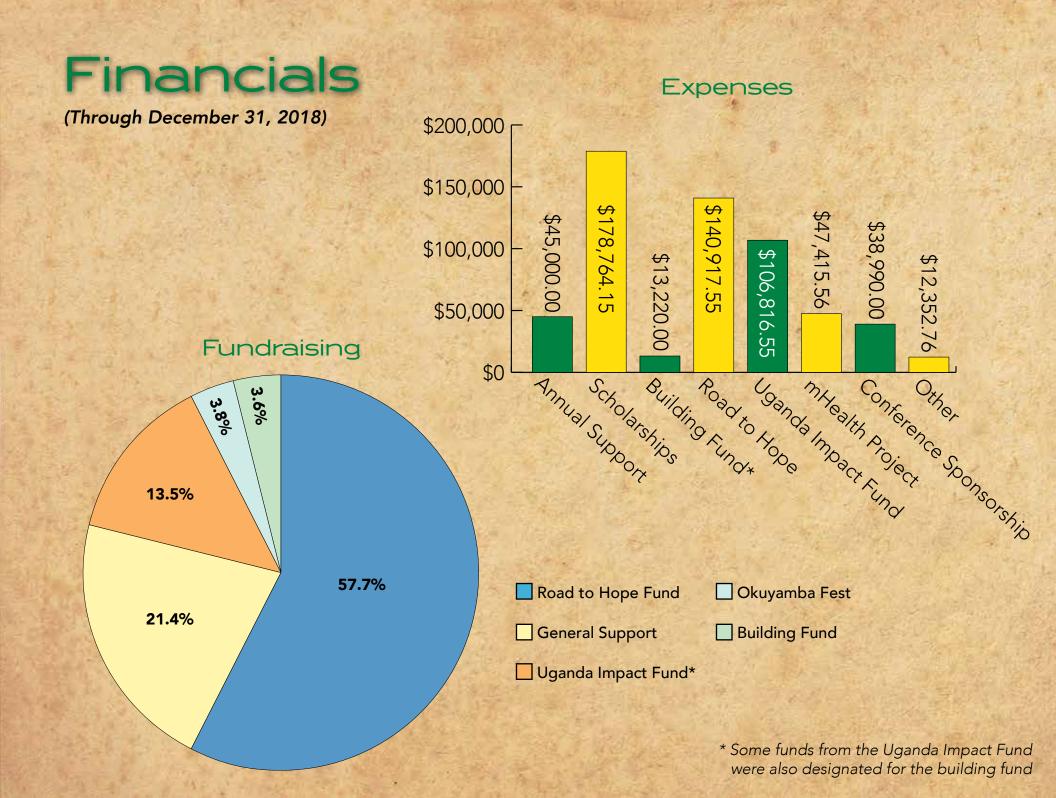












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