Friends of Ngora Hospice

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PROVIDENCE
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The presenters have nothing to disclose.
One Cause, Two Continents
Commit to a new friend in Africa
What is FHSSA?

• Began in 1999 as the Foundation for Hospices in Sub-Saharan Africa with the mission of building partnerships to enhance compassionate care in Africa.

• A non-profit organization that pairs U.S. hospices with hospice and palliative care organizations in 15 countries in Sub-Saharan Africa; to date, there are more than 90 partnerships
What is FHSSA?

• Promote mutually beneficial relationships between US and African organizations to foster idea-sharing, educational opportunities and professional exchanges.

• Generate financial support for the African organizations through the activities and fundraising efforts of the US partners.

• Engage US hospices in improving quality hospice and palliative care internationally.

• Develop international relationships in which participating organizations can serve as a support for one another.
Why did we decide to get involved?

• Fit with the Providence mission of caring for the poor and vulnerable through compassionate care
• Saw the opportunity to inspire our hospice staff and build a greater sense of community
• Impressed with FHSSA’s mission and approach
Sub-Saharan Africa

- Home to only 13% of world’s total population, but has 68% of people living with HIV/AIDS
- Of the world’s AIDS orphans, 89% live in Sub-Saharan Africa
UGANDA
Uganda Facts

• Incredibly diverse country with more than 40 distinct languages; official languages are English and Swahili

• Located in Eastern Africa; landlocked

• Same latitude as parts of Malaysia, Indonesia, Peru and Brazil

• Population: more than 35 million
Uganda Facts

• One of the world’s poorest nations

• Poverty especially prevalent in rural areas, where more than 85% of population reside

• Gender equality and other human rights and social issues
Health in Uganda

• Average life expectancy in 2011: 54 years
• Infant mortality rate (per 1,000) in 2011: 58
• # of physicians per 1,000 Ugandans: 8
• Prevalence of HIV/AIDS in 2011: 7.2%
• Approximately 6,000 women die each year due to pregnancy-related complications

Palliative Care in Uganda

- Uganda is a leader in palliative care and a role model for other African countries

- The only African country to give palliative care a priority in their National Health Plan

- The first African country to allow specially trained nurses to prescribe morphine, which helps to counter the challenges of physician shortage
Ngora Hospice

• Started in 2006 and is an active member of the Palliative Care Association of Uganda; connected with Ngora Hospital

• Yearly census of approximately 100 patients, primarily with diagnoses of HIV/AIDS, cancer and tuberculosis

• Has five paid staff and 10 Community Volunteer Health Workers (CVHWs) located in the Teso region in Northeastern Uganda, an extremely rural area

• Services usually provided on foot or by bicycle
Ngora Hospice Team: Sam (Ag. Director); Sister Rose Aliano (Team Leader); Jennifer (Palliative Care Nurse); Christine (Palliative Care Nurse); Patrick (Admin. Sec.).
“A Monthly Review Meeting, of the Palliative Care Team Members with Community Volunteer Health Workers” February 1, 2013
2012: “A social worker in front of Hospice offices with the only means of transport, for short distances.”
A Palliative Care Nurse, sorting out recently purchased drugs for home visits, including medications for pain management and other symptoms. Since poverty is a significant challenge for the majority of patients and families, some of them were also provided with relief materials such as sugar, soap, and mosquito nets.
Challenges faced by Ngora Hospice

• Inadequate funding
• Increasing numbers of patients
• Communication
• Significant poverty
• Caregiving
• Stigma and misinformation about illness and end of life
• Hostile weather conditions
• Lack of adequate and reliable transportation
2013: “A social worker rolling the motorcycle to a mechanic after it developed a deflated tire. This type of challenge can be very stressful especially when one is deep in remote Communities and the weather is bad e.g. when it is threatening to rain. Fortunately, in this occasion, the problem occurred on one of the main roads, on our way back from the field and it was a dry day.”
<table>
<thead>
<tr>
<th>DIAGNOSIS</th>
<th>SEX</th>
<th>OUTCOME</th>
<th>TOTAL</th>
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<tbody>
<tr>
<td></td>
<td>M</td>
<td>F</td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>08</td>
<td>13</td>
<td>21</td>
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<tr>
<td>HIV/AIDS</td>
<td>36</td>
<td>51</td>
<td>86</td>
</tr>
<tr>
<td>Both HIV/AIDS and Cancer</td>
<td>04</td>
<td>07</td>
<td>10</td>
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<tr>
<td>Other(s) e.g. stroke, sickle cell disease, diabetes, terminal kidney disease e.t.c.</td>
<td>29</td>
<td>20</td>
<td>48</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td><strong>77</strong></td>
<td><strong>91</strong></td>
<td><strong>165</strong></td>
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(source: Ngora Hospice quarterly report, April-June 2013)
Photos included from FHSSA website
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Objectives of Ngora Hospice

- Grow census to 300 by 2014/2015
- Support staff growth with compensation and transportation, including acquisition of two motorcycles and one vehicle
- Focus on holistic empowerment of families of terminally ill patients
- Identify unmet caregiving needs to learn more about root causes and how Ngora Hospice can help (education, respite, etc.)
- Promotion of safe water, sanitation and hygiene
Strategies of Ngora Hospice to Meet Objectives

• Networking with local and international HIV/AIDS and Palliative Care CSOs

• Increasing advocacy and lobbying efforts with private-sector and government leaderships

• Implementation of an IEC (Implementation, Education & Communication) program

• Promotion of Income Generating Activities (IGAs) for People Living with AIDS (PWLAs), cancer patients and their family members

• Currently undertaking a study: “Factors Affecting Ongoing Care of Patients by Community Volunteer Health Workers and Caregivers in Ngora” to be presented at PCAU biannual conference
Goals of Friends of Ngora Hospice

• To support Ngora Hospice in achieving their goals

• To develop an ongoing, collegial relationship with Ngora hospice, characterized by bi-directional communication and sharing.

• To increase awareness of palliative care needs in Africa and appreciate how quality care can be given with limited resources.

• To foster team building among members of Providence Hospice, collaborating around the common purpose of supporting Ngora hospice.

• To financially support Ngora hospice through local fundraising efforts.
Inspiring our Staff to Get Involved

• Began by gathering interest and commitment through staff meetings and educating about the healthcare challenges in Africa, specifically as they relate to palliative care

• Presented to leadership for approval

• Worked with FHSSA to eventually be connected with Ngora Hospice

• Began communication with Ngora Hospice via email, and Friends of Ngora Hospice was born
Staying Involved

• Conduct regular committee meetings to generate fundraising ideas, share correspondences with Ngora Hospice, update on projects and to educate staff on Uganda and surrounding areas.

• Have met and partnered with others in the community who have connections with Uganda.

• Use our twice-monthly hospice newsletter and all-staff meetings to keep department informed and involved.
Recent Fundraising Projects

• Fundraising
  – Bake sales
  – Sale of staff member’s handmade jewelry
  – Garage sale
  – Organ concert
  – Christmas ornament painting workshop
  – Okuyamba screening
  – Sweatshirt sale
  – Holiday Party and Auction
Hospice RN making jewelry to sell for Ngora Hospice at an all-staff craft fair
Providence Hospice staff and family members enjoying the ornament workshop
Hospice RN Susan working hard on her ornament
Providence Hospice Director Jane Brandes and her husband reviewing their bids at the Holiday Auction
Enjoying the evening
Enjoying the evening
Enjoying the evening
Showing off some items
Outcomes

• Core team of committed members of Friends of Ngora Hospice, along with Hospice-wide participation in fundraising and other activities

• Surpassed fundraising goals, raising over $8000 in first year

• Frequent and collaborative correspondence between partners
What’s Next?

• Continue building relationship with Ngora Hospice
• Innovate with new fundraising ideas
• Plan for staff visit/exchange
• Inspire other hospices to partner with one of the more than 20 African hospices currently on FHSSA’s waiting list
Q & A

![Question Mark](image)
RESOURCES

*FHSSA:  www.fhssa.org
Ph:  703-647-5176   Fx:  703-837-1233

*Friends of Ngora Hospice contacts:
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www.facebook.com/FriendsOfNgoraHospice
References

• World Health Organization, Uganda: http://www.who.int/countries/uga/en/


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• Quality of life among patients receiving palliative care in South Africa and Uganda: a multi-centered study; Selman et al. Health and Quality of Life Outcomes 2011, 9:21 http://www.hqlo.com/content/9/1/21

• Map Credit: Wikipedia, Uganda
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