Foundation for Hospices in Sub-Saharan Africa

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Quarterly Report

CELEBRATING YOUTH: St. Joseph's Care & Support Trust Commitment to Serve Community Children

Maria Magarete & Kleinbooi Mathebea

In celebration of Youth Day 2008, St. Joseph's Care and Support Trust located in Bronkhorstspruit, Mpumalanga South Africa held a Mr. & Miss St. Joseph's Youth Pageant on Saturday June 14, 2008. This pageant was different from any other primarily because it had nothing to do with looks, but was based on the contestants charisma and ability to be a good youth ambassador. The pageant was also unique in that it involved orphans and vulnerable children from the communities that St. Joseph serves.

St. Joseph's Orphan Care program has grown since its inception in 2001 with the goal of providing assistance to the both the psychosocial, educational and physical needs of Orphans and Vulnerable children in their care. The goal of the Youth Pageant was to not only empower the members of the community to accept responsibility for the care of their orphans, but to identify an ambassador amongst the youth and for the youth while joining communities together.

The St. Joseph's Youth Ambassadors

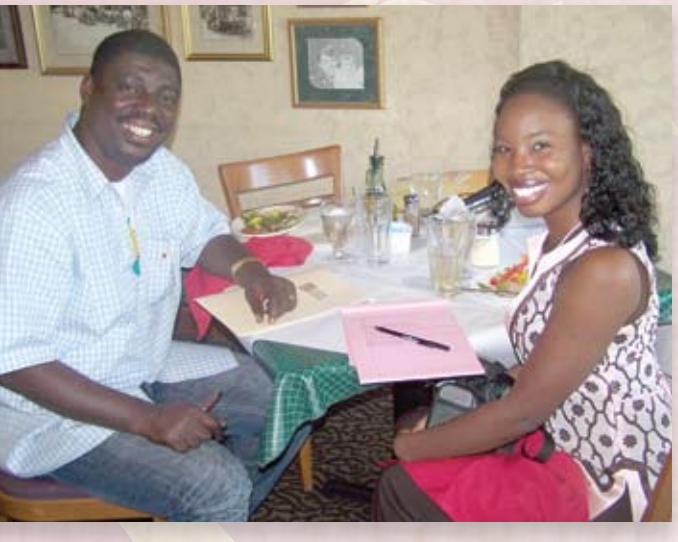
The day was filled with excitement. Over 500 youth from the communities surrounding Bronkhorspruit attended the event, eager to see who would be crowned the first ever Mr. & Miss St. Joseph's Youth. The event was filled with anticipation and cheering for the favorites. Entertainment included the Rethabiseng and Refilwe dancers as well as a couple of children who decided on the day that they would like to perform a poem or sing a song!

It was a tough decision for the judges to make as all 16 participants came across as strong competitors for the title. A congratulations goes out to Maria Magarete from Onverwacht and Kleinbooi Mathebe from Refilwe for winning the very first Mr. and Miss St. Joseph's Youth Pageant. They will be expected to represent St. Joseph's in the communities and be a role model and ambassador to their peers. Elisabeth Schilling, the Director of St. Joseph's feels that they will do an excellent job!

Coming in close second and third place was 1st Prince – Simphiwe Khumalo from Wolvenkop, 2nd Prince – Xolani Ndubatha from Ekangala, 1st Princess – Amanda Selala from Refilwe and 2nd Princess – Lerato Cheze from Ekangala.

Fighting Discrimination to Provide Care: Interview with Rev. Dr. Charles Abban

by Funmi Adesanya, FHSSA/NPI Program Assistant



Rev. Dr. Abban & Funmi Adesanya

In 1993, Rev. Dr. Charles Abban was a banker in Ghana who became touched by the poverty of those suffering around him. His compassion encouraged him to start the Miracle Rock Foundation (MIROF) which is an NGO that seeks to provide for the physical, mental, and spiritual needs of the less fortunate, including those affected and infected by HIV and AIDS. Through the support and endorsement of the Ghana AIDS Commission, the government, and other funders, the foundation became Rock Hospital in 2004 and now serves a population of over 800,000 and is also accredited by the National Health Insurance of Ghana.

Visit with Genesis Healthcare: L to R Sheila Everett, Manager; Rev. Dr. Charles Abban; Tim Patton, Chaplain; and Renee Sparks, Director.

Two years ago, Miracle Rock Foundation was partnered with Genesis Healthcare System in Zanesville, Ohio through FHSSA's Partnership Initiative. In a recent visit to the U.S., not only did Rev. Dr. Abban meet with his partners for the first time, where he was proclaimed as a "Citizen for the Day" by the mayor of Zanesville, but I was privileged to meet with him to discuss the challenges he faces in providing hospice and palliative care in his community.

In his frank discussion of the challenges Ghana and other African nations face he said "people need to understand that palliative care in Africa does not look like the West. We must fight to serve our patients against all odds with limited resources. We must fight against discrimination, we must fight against our own culture, and it pains me that we must face the fact that we fight against the discrimination of care alone."

Discrimination is often mentioned when discussing patient's experiences associated with care. Abban mentions that the fear of discrimination and medical service utilization are tightly linked in the communities he serves. If a patient seeks out medical attention for a disease or ailment, the condition can be seen as a curse and no one wants to be affiliated with a cursed individual.

"Patient's diagnoses are not disclosed because labeling contributes to family and community members disassociating with patients," replied Abban. A family member who finds out a patient is diagnosed with a certain disease or infection may not want to pay for services, particularly if the patient is going to die. Why pay for comfort drugs when the money can be saved and used for a proper funeral. "Many people believe that you must pay for your life choices. Family members will ask why should we pay for the results of a patient's life style? We spend a lot of time counseling patients and their families to alleviate the roots of discrimination and stigma."

Stigma and discrimination are some of the many challenges Abban faces on a daily basis. Many patients are visited in their homes because the idea of going to a hospital or hospice for care is associated with death and personal wrongdoing. This requires Abban and his staff to follow up with patients at home while not disclosing the reason for the visits. "We do not focus on the disease or the ailment but on the care and the comfort of the patient. The fact that we are there is all that matters."

When asked how some of the challenges Miracle Rock faces can be met, Abban responds by saying "Hope. We focus on hope, because hope allows us to serve our patients when we have nothing to offer them. We focus and draw on partnerships such as our partnership with Genesis Healthcare System in Ohio. Partnerships spread the message on the needs of palliative care and educate communities towards changing their mindsets about the discriminations they impose on their loved ones. We need increased support not only in Ghana but throughout Africa so that we can fight the fight against the discrimination and stigma associated with hospice and palliative care."

PEPFAR Re-Authorized by Congress

The legislation reauthorizing the President's Emergency Plan for AIDS Relief has been approved by the Senate and the House and is expected to be signed by President Bush shortly. FHSSA was able to include language describing 'comprehensive care' that will include palliative care in the legislation. There is also a provision that 50% of PEPFAR funds should go to care and treatment, which includes palliative care. FHSSA sees this as a great advancement for palliative care and looks forward to President Bush's signing of the bill into law. The total proposed budget for five years is $48B and will now move into the appropriation process. This amount will continue the current level of PEPFAR program activity, as well as expand the program from 15 to about 100 countries.

The Importance of Worldwide Opioid Availability

by Martha Maurer

Throughout the world, millions of adults and children are suffering from pain due to diseases such as cancer, HIV/AIDS, and sickle cell anemia. Unrelieved pain can destroy a person's quality of life by interfering with relationships, the ability to work, and physical activity. In some cases, severe pain can destroy the will to live. Patients with cancer or AIDS often have severe pain, particularly during the late stages of the disease. In the developing world, most cancers are diagnosed in late stages, when pain is usually the most severe.

Global health and drug regulatory authorities including the World Health Organization and other United Nations bodies concur that most moderate to severe pain accompanying cancer, AIDS, and other medical conditions could be relieved if relatively inexpensive opioid analgesics such as orally administered morphine, were adequately available and accessible to patients. However, it is estimated up to 70% of cancer patients and 80% of AIDS patients suffer needlessly because opioid analgesics are not available or are inaccessible due to tight regulations and laws governing their procurement, distribution, prescribing, or dispensing.

Opioid analgesics are internationally controlled under the United Nations "Single Convention on Narcotic Drugs, 1961." Thus, they are subject to special security and control requirements, which can contribute to inadequate availability. To successfully address this problem it is critically important to understand a country's drug control system (including procurement and distribution systems, national policies, and their implementation) and to work with the relevant national authorities (regulators and policymakers) to change the system.

As the global occurrence of cancer and HIV/AIDS continues to rise, the importance of opioid availability is becoming increasingly critical. Experts are predicting the number of people who develop cancer worldwide will double in the next decade, with the majority of new cases and deaths shifting from developed to developing countries. Although there has been some progress in stabilizing the spread of HIV/AIDS and in the successful implementation of programs providing ARVs, the global occurrence of HIV/AIDS, — particularly in Africa — continues to be a major concern. As the occurrence of diseases increases, relieving pain and suffering will be a growing problem which must be addressed.

The inadequate availability of opioid analgesics is the result of a number of barriers within countries, resulting in a low national demand for the importation, domestic production, and use of opioids. Barriers related to health professionals' knowledge and attitudes about opioid analgesics include inadequate professional training in pain, palliative care, and the use of opioid analgesics or a misunderstanding of addiction. Unduly strict national drug control policies are increasingly recognized to be among the most significant barriers to patient access to opioid analgesics for palliative care, especially in developing countries. While these barriers are unique to each country, advocacy must be strategically targeted on some of the common themes, such as restrictions on prescription quantity, complicated prescription forms, fears of legal sanctions, opioid cost issues, and inadequate methods for countries to estimate their annual opioid requirements.

The International Covenant on Economic, Social and Cultural Rights recognizes the right to health, which includes the control of disease and the availability of essential medicines, such as opioids for pain relief. Furthermore, access to pain-relieving medications is increasingly recognized as a human right by organizations such as the World Health Organization, the International Association for the Study of Pain, and the Worldwide Palliative Care Alliance. Palliative care advocates have developed a

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number of declarations calling for palliative care and essential medicines for the relief of pain as human rights.

Additionally, representatives of national governments, acting through their membership in high-level United Nations bodies, have called attention to the inadequate availability of opioid analgesics, and have requested governments to evaluate their national drug control policies for impediments and to improve the availability of opioid analgesics for medical purposes. These findings and resolutions form an imperative to all governments to address the problem on the inadequate availability.

Progress is being made. For the last decade, the Pain & Policy Studies Group (PPSG) has collaborated with the World Health Organization and the International Narcotics Control Board to develop methods to achieve more balanced national policies and administration, and has accrued experience in implementation and evaluation.

With support from the International Palliative Care Initiative of the Open Society Institute, PPSG has developed the International Pain Policy Fellowship (IPPF) to increase the global capacity to identify and correct regulatory barriers so government policies recognize opioid analgesics are indispensable for palliative care. The inaugural class of Fellows was convened in Madison, Wisconsin in October 2006 for a five-day training, and included Fellows from 8 countries: Argentina, Colombia, Nigeria, Panama, Serbia, Sierra Leone, Uganda, and Vietnam. Each Fellow was responsible for outlining their national drug availability action plan and timeline during the training. The 2008 class included Fellows from Armenia, Georgia, Guatemala, Jamaica, Kenya, Moldova, and Nepal, as well as representatives from the governments of Georgia, Guatemala, Jamaica, Kenya and Nepal.

The aim of the two-year Fellowship is to empower Fellows with the knowledge and skills that will help them to improve patient access to opioid analgesics for pain management. Through this work, the IPPF has the potential to lessen the crisis of under-treated pain in the selected countries by improving availability and patient access. The Fellowship program includes training, mentoring, action plan development, and an in-country pain policy project. Fellows are provided a modest salary stipend. Applications are accepted from mid-career physicians, health care administrators, policymakers, or lawyers from a health care facility, policy center, or university from low- or middle-income countries.

In Africa, the African Palliative Care Association has become a leader in advocacy for improving opioid availability. In June 2006, APCA hosted an opioid availability workshop for six countries: Ethiopia, Kenya, Malawi, Rwanda, Tanzania, and Zambia. In May 2007, a similar workshop was conducted for six western African countries: Cameroon, Cote d' Ivoire, the Gambia, Ghana, Nigeria, and Sierra Leone. Most recently, in February 2008, another workshop was held in Windhoek, Namibia for six southern African countries: Botswana, Lesotho, Mozambique, Namibia, Swaziland, and Zimbabwe. During the workshop, teams of health care professionals and drug regulators from each country worked together to identify barriers and develop a strategic plan to improve access. APCA continues to provide follow-up technical assistance.

It is important to understand the devastating effects of pain on people with cancer, AIDS, and other diseases or conditions, and the essential role opioid analgesics can have in relieving pain. The public health burden of disease can be reduced if pain can be relieved. The current lack of availability of opioid pain medicines paired with the HIV and cancer epidemics suggests pain and suffering is an increasing public health problem. There have been hopeful signs of progress in some countries, but it is not likely this progress is sufficient to counteract the deepening global disparities in access to opioid analgesics. Leadership focused on these efforts will be needed from international drug control bodies, national governments, and from individual health professionals.

The Foundation for Hospices in Sub-Saharan Africa
1700 Diagonal Road, Suite 630, Alexandria, Virginia 22314
703/647-5176 • www.fhssa.org • info@fhssa.org