

February 2008

Quarterly Report

World AIDS Day Messages Must Extend Beyond December 1st

Remarks made by Naomi Tutu at NHPCO's Clinical Team Conference in New Orleans

World AIDS Day, December 1, 2007.

o often, when we are shown the faces of AIDS, we are shown faces that we might not bump into at the grocery store, that are not people likely to be sitting next to us in church, but the reality is that the face of AIDS is the face of our sisters, our brothers, ourselves.

So very often, when we speak of those living with HIV and AIDS, we paint them as though they were sitting back, waiting for us to come and save them. When the truth is they are the people at the forefront, caring for each other, educating the world. And what they ask of us is that we also speak up, that we don't try to act as though AIDS does not exist, that we



Naomi Tutu with Don Schumacher, President of NHPCO & FHSSA during NHPCO's Clinical Team Conference

don't try to hide those who we know in our family are HIV-positive or living with AIDS. All that they ask is that we join our voices with theirs in demanding that the promise we made as a world community—to stop AIDS by 2015—is achieved.

And we can achieve it.

We can achieve it if we educate ourselves and our children about safety. We can achieve it if we pressure our governments and drug companies to make sure that those living with HIV and AIDS throughout the world have access to the medications that they need. We can achieve it when we show our care for those living with HIV. And show care to those dying of HIV and AIDS.

In too many parts of the world, those dying of AIDS are left to care for each other or to be cared for by children or the very elderly. In too many places, people dying from AIDS are dying in pain, when we know that we have the drugs and the ability to make sure that is not the case.

I ask you today to pledge that you will do what you can, where you are, to make sure that we as a world community live up to our pledge to have an AIDS free world by 2015.



Hospice patient Smangele with children

Partnerships Build Relationships Through Visits

A partnership visit between Lifetime Care, Hospice of Rochester, New York and Zululand Hospice, South Africa

Notes from Erma Perkins

ast year, Edwina Daniels, Ruth Hogan, Gail Hubbard and I arrived at the Rochester Airport, each with 100 pounds of vitamins, baby clothes, medical supplies, educational materials on children and grieving, hygiene kits, and personal items for a flight to Johannesburg, South Africa. Upon arrival, we were met by Peter Terry-Lloyd, Manager of Zululand Hospice and Audrey, a nurse.

After emptying our suitcases at the office, I accompanied Peter to the Empangeni office and met with Jane, Director of nurses and Lynn, the fund-raiser. They shared ideas and showed me the records Jane compiles every month for their funders. They hope to develop a program aimed at supplying one new outfit for each of the vulnerable children of their patients. These uniforms will be given at the beginning of the January 2008 school year.

Our trip exposed the day-today challenges and many great needs Zululand Hospice faces. One in particular, was a visit with Smangele, a 41 year old woman with AIDS. Selina, one of the Zululand nurses, had been trying to convince Smangele to go on anti-retroviral meds (ARVs). After many visits by Selina and much discussion, Smangele finally consented to take the medication. Her CD4 count originally 165 several months ago is now 25. It is unlikely that she will survive long enough to respond to the ARVs.

The impact of firsthand witness to the need is multiplied many times over what we receive from pictures and reading. Our next visit will be at the end of May 2008. You may think of a visit to Zululand Hospice as a once in a lifetime trip, but be warned - you will likely want to repeat it. The country, the people, the opportunity to support such significant work may grab you and not let you go. I am grateful for the opportunity to support the work of Lifetime Care's partner, Zululand Hospice in KwaZulu Natal, South Africa.

Learn more about Partnerships at www.fhssa.org.

Successful Stakeholders' Meeting APCA

In Moshí, Tanzanía

he Evangelical Lutheran Church of Tanzania (ELCT) in collaboration with the Foundation for Hospices in Sub-Saharan Africa celebrated a successful Stakeholders' Meeting in Arusha, Tanzania, October 2007 for a project called "Continuum of Care for Persons Living with HIV/AIDS in Tanzania" (CHAT).

FHSSA was awarded the three year grant by the US Government through the President's Emergency Plan for AIDS Relief (PEPFAR) and managed by the United States Agency for International Development (USAID). ELCT is the main implementer of the program in Tanzania. The African Palliative Care Association (APCA) is providing monitoring and evaluation (M&E) and training expertise.

The overall aim of CHAT is to scale up and integrate palliative care services within existing ELCT hospital systems, building upon a model program developed by Selian Lutheran Hospital Hospice and Palliative Care program's "Tanzanian Model." During the stakeholders' meeting, over fifty participants from 12 targeted hospitals, assistant bishops from 10 involved dioceses, leadership from ELCT headquarters, representatives from critical partners including FHSSA, APCA, the Tanzania Palliative Care Association (TPCA), the Ministry of Health (MoH) in Tanzania, the Christian Social Services Commission (CSSC), Family Health International (FHI), Pathfinders International, Interchurch Medical Association, American International Health Alliance (AIHA), Mildmay

International and the Kilimanjaro Christian Medical Centre (KCMC) all joined together to exchange ideas, project information, voice concerns and take ownership of the project.

The meeting opened with thoughtful presentations on various aspects of palliative care in Tanzania from the newly elected Presiding Bishop of ELCT, Rev. Malasusa, Director of CSSC, Dr. Kimambo, and a representative from the MoH, Dr. Mbatia. Panel discussion and brainstorming sessions addressing the topics of finance, education, M&E, and human resources provided a forum for key challenges to be addressed, solutions to be agreed upon and commitments made to the CHAT project goals and focus. Participants left the meeting with a great understanding that the patient is the primary focus of the program and sustainability of the project is possible through community ownership of CHAT.

Working closely with FHSSA over the next couple of months, the ELCT headquarters team will be conducting palliative care trainings for Palliative Care Coordinators and their Assistants, working with APCA to ensure a M&E and reporting system is up and running, as well as preparing hospital sites for full program implementation.

For more information, please contact:

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APCA and FHSSA Contínue to Work Together

he African Palliative Care Association and FHSSA continue to work closely together. At the September 2007 APCA Conference in Nairobi, "Partnership Manual on One-to-One Partnerships" was published. This manual sets forth the guidelines and processes we will follow in co-managing partnerships between African and American hospice and palliative care programs.

This year, APCA and FHSSA are committed to working together on similar areas, including technical assistance and scaling-up grants for which APCA will be the lead agency.

Technical assistance refers to the use of loaned technical experts who provide focused, outcomeoriented interventions at hospice and palliative care organizations with the goal of helping them further development and delivery of standards-based palliative care.

Scaling-up refers to the program development needed to begin, enhance, or extend palliative care services in any public, private, or community setting. Scaling-up can take place in hospitals, clinics, or home-base care settings by incorporating palliative care with appropriate training, supervision, comprehensive holistic care, and supply chain for medications.

Together, APCA and FHSSA hope to move forward towards the realization of quality, affordable, culturally appropriate palliative care – accessible to all in need in Africa.





FHSSA Co-Sponsors Conference on Access to Analgesics for Southern Africa



he African Palliative Care Association is holding its third regional conference on access to essential pain medicines, "Advocacy for Palliative Care in Africa: A focus on essential pain medication accessibility in Southern Africa," which will be held Feb 27 – 29, 2008 in Windhoek, Namibia.

The conference will bring together sixperson country teams from Namibia, Lesotho, Swaziland, Botswana, and Mozambique to meet with experts in medication availability and treatment. During these conferences, attendees receive training and develop follow up action plans to overcome barriers to accessing controlled medications needed for palliative symptom management of HIV, cancer, and other life threatening illnesses. Laws and regulations often limit access to drugs like opioids due to fear of illicit use.



The United Nations and the World Health Organization both support the appropriate medical and scientific use of these drugs with proper safeguards and effective prescriber training. This APCA conference is being funded by USAID with support from WHO, FHSSA/NHPCO, the Pain and Policies Study Group at University of Wisconsin, and the Open Society Institute. The first of these conferences was held in Uganda for East African countries in June of 2006, the second was held in May of 2007 in Ghana for West African countries. Access to and availability of these medications is essential for Africans to receive quality palliative care.

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