



Impacts of PEPFAR re-Authorization on Palliative Care

by Dr. Joseph O'Neill

he President's Emergency Plan for AIDS Relief is the largest public health measure directed against a single disease in history. After decades of neglect and absent leadership, the HIV/ AIDS epidemic in Africa and elsewhere in the developing world began to receive funding commensurate with need when President George W. Bush signed legislation he proposed in his 2003 State of the Union Address.

PEPFAR is now marking its fifth anniversary and there is a great deal to celebrate indeed: The Office of the Global AIDS Coordinator at the U.S. Department of State estimates that some 1.4 million men, women, and children have received antiretroviral treatment. Additionally, HIV parent to child prevention services were provided during 10 million pregnancies and supportive care was extended to 6.6 million individuals as a result of U.S political leadership and taxpayer generosity.

One of the things not captured in these statistics is the impact that PEPFAR has had on palliative care in sub-Saharan Africa and the developing world. The original PEPFAR legislation specifically endorsed and generously supported funding for palliative care. While subsequent experience has made it clear that the forefathers and mothers of PEPFAR did not hold the identical definition of "palliative care" as do specialists in the field, there can be no argument that institutions providing palliative care in Africa have received attention and financial support that they otherwise would not have.

The African Palliative Care Association (APCA), long and generously supported by the Diana Princess of Wales Memorial Fund, received funding directly from PEPFAR coffers in 2004 that allowed it to hire its first full-time Executive Director and institutionalize continent-wide activity. Our own Foundation for Hospices in sub-Saharan Africa has garnered substantial funding from PEPFAR's new partner initiative to develop palliative care services across Tanzania. Many other palliative

care providing initiations have been supported through individual country specific plans developed with PEPFAR funds and technical guidance.

Perhaps the most important achievement in all of this is the fact that public health officials across the globe are now thinking about palliative care. The simple fact that this historic piece of legislation targeted palliative care has made those who administer its programs and develop its policies ask the question "What is palliative

NHPCO, FHSSA, and APCA have been answering that question clearly and often. It is not uncommon to find our leadership in Congressional, PEPFAR offices and in embassies around the world advocating for the type of services we know people living and dying with HIV/ AIDS need. FHSSA and APCA officials recently met with the White House Chief of Staff in the West Wing to encourage sustained administration support for palliative care.

These advocacy activities have been especially important this year as the PEPFAR legislation must be renewed by Congress now and every five years hence. A great deal of work has already been devoted to reauthorization and bills have made substantial progress through Congress. At the time of this writing debate continues regarding the level of funding, the need to specifically mention palliative care in the final language and several other points.

There is, however, no doubt that ultimately President Bush will be able to sign a reauthorized PEPFAR bill into law in the near future. When he does so, we should all take a moment to reflect on the tremendous good that a foreign policy based on compassion and intelligent use of health resources can do and to recommit ourselves to extending the embodiment and practice of compassion that we know as palliative care to the rest of the world.



























































Hospice and Palliative Care Work in Africa Acknowledged During MLC 2008



L to R: Bishop Kevin Downing, Dr. Faith Mwangi-Powell, Phil Di Sorbo, Dr. Stephen Connor and Barbara Campbell-Ker during Congressional Hill Visits.

uring NHPCO's recent Management and Leadership Conference, April 9-12 in Washington, DC, themes focusing on international developments in hospice throughout Africa were prominent during the week. Bishop Kevin Downing, keynote speaker during FHSSA's networking breakfast, shared individual stories of hospice patients and urged members of the hospice and palliative care community to tell stories and share the global needs of the infected and affected. FHSSA leadership and special quests carried these messages to the halls of Capitol Hill during the week.



L to R David White, Lisa Motz-Storey, Alex Shade and Funmi Adesanya at FHSSA Booth during MLC's Exhibit Reception.

FHSSA was pleased to have in attendance Andre Wagner from the Hospice and Palliative Care Association of South Africa as well as members from Witswatersrand Hospice in South Africa who are partnered with The Hospice of the Florida Suncoast.

Dr. Faith Mwangi-Powell accepted the International Founder's Award on behalf of the African Palliative Care Association for APCA's expertise and successes of promoting quality palliative care, education, and service provision throughout the continent.

Dr. Mwangi-Powell stated that, "we succeed because we are riding on the shoulders of giants" noting that the collaborative work with FHSSA, NHPCO and other partners has brought more attention and support to hospice initiatives on the continent enabling APCA to become more successful in its expansion, work and growth.

FHSSA looks forward to hosting future events that advance hospice and palliative care throughout Africa.

2008 FHSSA Board of Directors

FHSSA is honored to welcome four new members to its board, Bob Clarke, David Lee, Stanley Straughter, and Christine

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Care-for-the-Caregiver" - An Essential Component of Palliative Care

by Phil Di Sorbo, FHSSA Senior Technical Advisor



Patient with family and caregivers in Chittora, 7imhahwe.

ne of the most significant Work Projects among Hospice Partnerships has been staff wellness programs that are a beginning attempt at comprehensively addressing the overwhelming caregiver burden being experienced throughout sub-saharan Africa today. In palliative care programs throughout the world, the quality of care provided is directly linked to the quality of staff and volunteers who deliver the care. Not only technical proficiency, but the physical, emotional, and spiritual well-being of staff and volunteers is crucial. In sub-Saharan Africa, staff and volunteer caregivers are under tremendous strain due to ever increasing caseloads, settings of extreme poverty and hunger, and ongoing cumulative loss of patients, friends, family, and-in many

Hospice (Zimbabwe) have conducted Carefor-the-Caregiver programs at South Coast and Tapologo Hospices in South Africa. These programs include dedicated time for staff and caregivers simply to express their own feelings using creative arts (particularly music, dance, and massage) and spirituality. The program facilitators simply offered the context and encouragement. Social Workers, nurses, volunteer caregivers, and even physicians, shared at the end of each session how very much they need to have their "well" replenished. Many expressed their multiple grief issues from losing not only their patients, but their family, neighbors, and friends continually. Many expressed a sense of being "used up" with no time for themselves. An important part of Care-for-the-Caregiver efforts became learning tools for self-care (massage, art, bereavement processes, spirituality, music/movement, prayer) just for oneself.

Care-for-the-Caregiver programming has at least the following three components:

- ongoing opportunities for staff to unwind, share their most personal feelings, and express themselves ritually
- training of supervisors in the use of staff support mechanisms, as well as how to identify staff and volunteers at risk for burnout and to take appropriate interventions
- incorporation of Care-for-the-Caregiver programming as an essential program component for quality care, with attention at the governance and senior management level for its use and effectiveness

The people of Africa are its treasure and the backbone of its palliative care movement. The imperative that exists today for access and quality will only be realized through the active support, nourishment, protection, and growth promotion for the human beings who deliver the care.

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