

Foundation for Hospices in Sub-Saharan Africa

October 2007

# Juarterly Report

### FHSSA-APCA Partnership Management

#### Partnership Programme Guidelines

ne-To-One Partnerships: APCA and FHSSA" was presented at the recent successful conference of the African Palliative Care Association in Nairobi, Kenya. It is a programme guideline for establishing engaged partnerships between African and American palliative care programs. The document describes the procedures that will be used to establish new partnerships, including the role of African National Hospice and Palliative Care As-

sociations. The partnership managers at APCA and FHSSA will oversee the programme. To preview the document, visit the APCA and FHSSA website.

"There are now 54 African/American active African/American partnerships. With the new Guideline publication and extensive interest at the recent APCA conference, more are expected. American hospices interested in partnering should contact FHSSA."

*Pictured here are Abby Baguma, APCA Partnership Manager, and Dr. Faith Mwangi-Powell, APCA Executive Director.* 







**Toll Free:** 877-470-6472

By Mail: **Diana Legacy Fund** Po Box 6058 Washington, DC 20042-6058

### Diana Legacy Fund Grows

his is the inaugural year of The Diana Legacy Fund a major fundraising vehicle for scaling up hospice and palliative care in Africa. American hospices, churches, organizations, businesses, and concerned individuals are asked to help launch the fund by donating and by engaging local media and constituents in publicizing it. Contact the National Hospice Foundation at

703-516-4928 for more information on how you can help.

Bishop Kevin Dowling, head of the Tapologo HIV/AIDS Programme in South Africa, was the Keynote Speaker in the first Diana Legacy Fund Regional event held recently in Detroit.



### Alexzandra Shade New Partnership Manager

HSSA welcomes Alex Shade as its new Partnership Manager. Alex will be stationed at the FHSSA headquarters in Alexandria, Virginia and will be available to visit and coach existing and developmental American hospices and other institutions involved in partnering. She will work closely with Abby Baguma, her counterpart at APCA in co-managing African/American partnerships.

Alex comes to us from LEAD where she was the Executive Organizer and helped develop many faith-based social action projects.

### World AIDS Day Event at NHPCO Conference: Partners Welcome

HPCO's Annual Clinical Team Conference (November 29th - December 1<sup>st</sup> in New Orleans) will include a FHSSA World AIDS Day Event at 5:30 pm on Friday, November 30th. The conference itself is

another opportunity for American partners to sponsor their African colleagues for a partner visit and an educational opportunity. Speakers at the Worlds AIDS Day event will include representatives from APCA, UNAIDS, and Seke Rural Hospice in Zimbabwe.

## Hospice and Palliative Care Association of South Africa

Celebrating the establishment of a FHSSA office with HPCA of South Africa are (from left to right) back row: Phil Di Sorbo, Liz Gwyther, Jennifer Tymon, Delshe April, Augie Tvrz, Andre Wagner, Alison v.d. Merwe; front row: Jenny Mills, Sally Singh, Lindi Mpololo.

A HPCA/FHSSA memorandum of understanding was signed in May by HPCA Director Dr. Liz Gwither and FHSSA Executive Director Phil Di Sorbo. Furthermore, FHSSA would like to announce that Jennifer Tymon has accepted a new position with APCA and now is living and working in Namibia as the Palliative Care Program Coordinator for a PEPFAR sponsored grant in Namibia."









### Donate Your Frequent Flyer Míles: Register Today

HSSA is now accepting certificates of donated frequent flyer miles in specified lots of 25,000 miles. These donations will be used to support partnership visits and technical assistant projects. For more information and a certificate to be completed, contact FHSSA today or visit the FHSSA web site at www.fhssa.org.

### Direct Relief International



HSSA Executive Director Phil Di Sorbo and Direct Relief Executive Director Thomas Tighe signed Memorandum of Understanding earlier this year, paving the way for the expansion of Direct Relief's supply chain of palliative care supplies to African hospice programs.

Participating in the Ceremony (from left to right) back row: Sandy Knox-Johnston, Jennifer Tymon, Faith Mwangi-Powell, Anthoula Randopolous, Lucy Anderson; front row: Thomas Tigue and Phil Di Sorbo.

### Dr. Mark Jacobson to Chair APCA Board

he Africa Palliative Care Association Board of Directors has elected a new Chairperson. Assuming a 3 year term, Dr. Mark Jacobson is the new Board Chair, succeeding the inaugural Chair, Kath Defilippi. Dr. Jacobson has served initially on the steering committee which brought APCA into being and has served on the APCA Board of Directors since its inception as Treasurer of the Board.

Dr. Jacobson has served as a physician and administrator for the Evangelical Lutheran Church in Tanzania since 1985 pioneering the development of the Selian Lutheran Hospital and Hospice in Arusha, Tanzania. He was also a founding member of the Tanzania Palliative Care Association, and also serves on that Board of Directors.



Since 2001, Selian Hospice has partnered through FHSSA with The Denver Hospice in Denver, Colorado. The Selian/Denver Partnership is a model FHSSA Partnership, with all best practice guidelines met and exceeded. We all congratulate Mark on his new leadership role at APCA, and pledge our continued active support for APCA and all its initiatives to scale up palliative care in Africa.

### APCA's mission is to promote and support affordable and culturally appropriate palliative care throughout Africa.

*St. Luke's Hospice in Cape Town and Hospice of Michigan, headquarterd in Detroit, have extablished a partnership effective September, 2007. APCA, HPCA, and FHSSA are pleased to welcome them to the partnership family."* 

### Palliative Care for Children

Author: Joan Marston; Paediatric Palliative Care Manager: Hospice Palliative Care Association of South Africa; Chair: International Children's Palliative Care Network

 hildren and young people with life-limiting conditions have very specific palliative care needs that are often different to those of adults.

This is recognized by the World Health Organization which defines palliative care for children as similar but different to the palliative care needs of adults. According to WHO, palliative care for children provides care to the child's body, mind, spirit and support to the family as well as the community into the bereavement period. Moreover, care may be provided even when there is treatment aimed at cure and may continue over many years where children have long-term chronic conditions.

An understanding of childhood development and an ability to assess a child's developmental age should be used in the assessment, planning and provision of palliative care. Communication through interpreting facial expressions and body-language in babies and children, play, art, music and stories; and developing the necessary skills for these, is stimulating (and fun!) for both the child and the palliative care professionals. Childhood bereavement support also requires a different approach aimed at promoting resilience.

Pain and distressing symptoms are often under-diagnosed and poorly treated, as few health professionals are trained in paediatric palliative care, and many fear using opioids for children. Improving access to paediatric palliative care drugs including opioids, as well as access to services is an important advocacy issue in many countries.

A major challenge is to develop accredited education and training courses, and then to implement these in all parts of the world, especially the developing world where so many children are infected with HIV, as well as affected by many other life-limiting conditions, and where infant mortality rates are high.

The International Children's Palliative Care Network, with its' head office in South

Africa and representation from all areas of the world, has been established so that palliative care programmes for children may share their knowledge and expertise, and be an international voice for children with life-limiting conditions both nationally and internationally.

Joan Marston Paediatric Palliative Care Manager at the Hospice Palliative Care Association of South Africa is shown here with paediatric patients.



