



**Canadian Hospice Palliative Care Association**

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**Association canadienne de soins palliatifs**

**HIV/AIDS and Hospice Palliative Care: A Global Response**

**Communication Toolkit**

**November 2009**

# Table of Contents

<b>Introduction</b> .....	3
<b>International Hospice Palliative Care Resource Commons</b> .....	4
<u>What is the Commons?</u> .....	4
<u>How to Navigate the Commons?</u> .....	4
<u>Links to the Commons</u> .....	5
<u>International Hospice Palliative Care Resource Commons Brochure</u> .....	5
<b>International Links</b> .....	6
<b>International Cooperation Committee</b> .....	7
<b>Provincial, National and International Conference/Workshop Dates</b> .....	8
<b>International Satellite</b> .....	10
<b>International Challenge Panel</b> .....	11
<b>Worldwide Hospice Palliative Care Alliance</b> .....	12
<u>Media Toolkit</u> .....	12
<u>Advocacy Toolkit</u> .....	12
<b>Twinning</b> .....	13
<u>HIV/AIDS Twinning Partnerships:</u> .....	14
<b>Appendix A</b> .....	15
<u>International Hospice Palliative Care Resource Commons Brochure</u> .....	15
<b>Appendix B</b> .....	16
<u>HIV/AIDS in Africa: Building North-South Partnerships</u> .....	16

# Introduction

The Canadian Hospice Palliative Care Association (CHPCA) is the national association which provides leadership in hospice palliative care in Canada. The CHPCA offers leadership in the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness and grief are lessened. As part of its mandate, the CHPCA allocates time and resources to HIV/AIDS and end-of-life care.

There is a lack of policy and program information for the HIV/AIDS and hospice palliative care population. In most African countries hospice palliative care services, including pain and symptom management, are very limited or non-existent. The development of the online resource commons will improve sharing and collaboration of hospice palliative care service information by making it easily accessible to all countries.

The CHPCA has developed a communication toolkit that will give you access to networking processes and tools that permit greater access to international and Canadian best practices in the field of HIV/AIDS and hospice palliative care. The communication toolkit will aim to raise awareness amongst hospice palliative care needs of developing countries, and allow all users to have access to valuable resources and links. The toolkit will promote ongoing learning between domestic and global responses to HIV/AIDS by providing information and links. The resources available in the commons are intended for the care of both adults and children, although some may be specific.

# International Hospice Palliative Care Resource Commons

## What is the Commons?

The CHPCA is pleased to announce the launch of a new on-line International Hospice Palliative Care Resource Commons for uploading and sharing resources related to international and domestic issues and end of life care. The International Resource Commons will be accessible through the CHPCA web site.

The new online International Hospice Palliative Care Resource Commons accessible through [www.chpca.net](http://www.chpca.net) will create a national online repository for resources. The commons will enable health care professionals and individuals to share international resources and will ultimately provide the opportunity for future collaborative resource development. Users of the International Hospice Palliative Care Resource Commons are able to search and download resources, as well as upload and share resources with the health care professionals, family and informal caregivers across the country and internationally.

## How to Navigate the Commons?

The International Hospice Palliative Care Resource Commons is organized into the following categories and sub-categories:

### Categories:

- Twinning
- Advocacy
- HIV/AIDS
- World Hospice Palliative Care Day
- Media

### Sub-Categories:

- Caring
- Caregiver
- Financial
- Loss, Grief and Bereavement
- Support
- Pain Management
- Policy

You can either **browse** the International Hospice Palliative Care Resource Commons or **search** using key words.

- You can **browse** within each category or within a sub-category. You will see a list of all of the items. Just select the desired category and hit search.
- You can **search** the International Hospice Palliative Care Resource Commons by typing in a keyword. You can choose to search the whole Commons by simply typing in your keyword in the box provided. Or you can narrow your search by selecting a category before searching on your keyword – or narrow it further by selecting a sub-category.

## **Links to the Commons**

Please go to any of the links below to access our International Hospice Palliative Care Resource Commons.

<http://www.peolc-sp.ca/international/english/>  
<http://www.peolc-sp.ca/international/francais/>

<http://www.chpca.net/home.html> and scroll to the Resource Commons Link  
<http://www.acsp.net/debut.html>

## **International Hospice Palliative Care Resource Commons Brochure**

Our International Hospice Palliative Care Resource Commons brochure outlines a description of the commons. This brochure will be distributed at all the CHPCA national conferences, highlighted in the CHPCA AVISO newsletters, and the brochure will be highlighted in the CHPCA monthly updates. The AVISO newsletter is distributed three times a year to over 3000 members. The CHPCA monthly update reaches over 5000 participants.

Please see below for links that will direct you to the on-line International Hospice Palliative Care Resource Commons.

[http://www.chpca.net/doctors\\_portal.html](http://www.chpca.net/doctors_portal.html)  
[http://www.chpca.net/nurses\\_portal.html](http://www.chpca.net/nurses_portal.html)  
[http://www.chpca.net/pharmacists\\_portal.html](http://www.chpca.net/pharmacists_portal.html)  
[http://www.chpca.net/physiotherapists\\_portal.html](http://www.chpca.net/physiotherapists_portal.html)  
[http://www.chpca.net/socialworkers\\_counsellors\\_portal.html](http://www.chpca.net/socialworkers_counsellors_portal.html)  
[http://www.chpca.net/spiritual\\_advisors\\_portal.html](http://www.chpca.net/spiritual_advisors_portal.html)  
<http://www.chpca.net/whatsnew.html>

Please see Appendix A for the International Hospice Palliative Care Resource Commons Brochure.

## International Links

The links below are organizations that are involved in hospice palliative care and HIV/AIDS. We believe these links will be able to help you network and stay informed.

1. African Palliative Care Association: <http://www.apca.org.ug/>
2. American Academy of Hospice and Palliative Medicine: <http://www.aahpm.org/>
3. Asia / Pacific Hospice Palliative Care Network: <http://www.aphn.org/>
4. Centre to Advance Palliative Care: <http://www.capc.org/>
5. Eastern and Central Europe Palliative Care Task Force:  
<http://www.oncology.am.poznan.pl/ecept/emenu.php>
6. Education in Palliative and End-of-Life Care: <http://www.epec.net/EPEC/webpages/index.cfm>
7. European Association for Palliative Care: <http://www.eapcnet.org/>
8. Foundation for Hospices in Sub-Saharan Africa:  
<http://www.fhssa.org/i4a/pages/index.cfm?pageid=1>
9. Hospice Education Institute: <http://www.hospiceworld.org/>
10. Indian Association of Palliative Care: <http://www.palliativecare.in/>
11. International AIDS Society: <http://www.aids2010.org/>
11. International Association for Hospice and Palliative Care: <http://www.hospicecare.com/>
12. International Association of Physicians in AIDS Care: <http://www.iapac.org/>
13. International Children's Palliative Care Network: <http://www.icpcn.org.uk/>
14. International HIV/AIDS Alliance: <http://www.aidsalliance.org/HomePagedetails.aspx?Id=1>
15. International Observatory on End of Life Care: <http://www.eolc-observatory.net/>
16. International Pain and Policy Studies Group: <http://www.painpolicy.wisc.edu/>
17. International Palliative Care Network: <http://www.palliativecarenetwork.com/aboutus.htm>
18. Latin American Association for Palliative Care: <http://www.cuidadospaliativos.org/>
19. Open Society Institute – International Palliative Care Initiative:  
<http://www.soros.org/initiatives/health/focus/ipci>
20. Palliative Care Australia: <http://www.palliativecare.org.au/>
21. Pallium India: <http://www.palliumindia.org/>
22. The National Hospice Palliative Care Organization:  
<http://www.nhpco.org/templates/1/homepage.cfm>
23. World Health Organization – Palliative Care:  
<http://www.who.int/hiv/topics/palliative/PalliativeCare/en/>
24. Worldwide Palliative Care Alliance: <http://www.thewpca.org/>

## **International Cooperation Committee**

The International Cooperation Committee of the Canadian Hospice Palliative Care Association conducted a national survey to identify resources, programs and services relating to hospice palliative care and HIV/AIDS (referenced as HPC and HIV/AIDS).

The purpose of the survey was to gather and build a Canadian inventory of domestic policy, programs and resources relating to hospice palliative care and HIV/AIDS. The survey went out to National HIV/AIDS community, Local AIDS Service organizations reached through the Canadian Aids Society membership list. It was also sent to key international HPC partners. The survey was conducted and sent out in June 2009 with a closing date of August 2009.

The results from this survey will help us to develop networking processes and tools that permit greater access to Canadian best practices in the field of hospice palliative care and HIV/AIDS. The survey results also fed in to the development of the International Hospice Palliative Care Resource Commons.

## Provincial, National and International Conference/Workshop Dates

- November 6-7, 2009 **Cuisle Beatha - International Palliative Medicine Conference**  
Galway, Ireland <http://www.cuislebeatha.ie>
- November 24-27, 2009 **Help the Hospices Conference 2009**  
Harrogate, England [conference@helpthehospices.org.uk](mailto:conference@helpthehospices.org.uk)
- March 4-7, 2010 **Leading Together 2010  
The 6<sup>th</sup> Annual HIV/AIDS Skills Building Symposium**  
Montreal, Quebec [www.cdnaids.ca](http://www.cdnaids.ca)
- April 17-20, 2010 **OPCA/HAO Joint Conference**  
Sheraton Parkway Toronto North Hotel  
Toronto, ON <http://www.ontariopalliativecare.org/>  
<http://www.hospice.on.ca/>
- May 10-11, 2010 **20th Annual Conference of the Réseau de soins palliatifs du Québec - La force de l'héritage: Source de dépassement**  
Quebec City, Quebec [www.reseaupalliatif.org](http://www.reseaupalliatif.org)
- May 31- June 1, 2010 **Reflections 2010 Provincial Palliative Care Conference, Saskatchewan Hospice Palliative Care Association Inc. and Sun Country Health Region**  
2010 Regina, SK [www.saskpalliativecare.org](http://www.saskpalliativecare.org) or [www.suncountry.sk.ca](http://www.suncountry.sk.ca)



## Provincial, National and International Conference/Workshop Dates

June 2-3, 2010	<b>9<sup>th</sup> Annual Kaleidoscope International Palliative Care Conference</b> Dublin, Ireland	<a href="http://www.stfrancishospice.ie/education/kaleidoscope.htm">www.stfrancishospice.ie/education/kaleidoscope.htm</a>
July 18-23, 2010	<b>XVIII International AIDS Conference</b> Vienna, Austria	<a href="http://www.aids2010.org/">http://www.aids2010.org/</a>
September 15-17, 2010	<b>Palliative Care in Africa: Creativity in Practice</b> Namibia, Africa	<a href="http://www.apca-windhoek2010.com">www.apca-windhoek2010.com</a>
September 23-24, 2010	<b>The Changing Landscape of Palliative Care - 19<sup>th</sup> Annual Provincial Conference</b> Winnipeg, MB	<a href="http://www.manitobahospice.mb.ca">www.manitobahospice.mb.ca</a>
October 5-8, 2010	<b>18<sup>th</sup> International Congress on Palliative Care</b> Montréal, Canada	<a href="http://www.palliativecare.ca/en/index.html">http://www.palliativecare.ca/en/index.html</a>
October 28-31, 2010	<b>2010 Canadian Hospice Palliative Care Conference</b> Ottawa, Ontario	<a href="mailto:mpeterson@chpca.net">mpeterson@chpca.net</a>

## International Satellite

The CHPCA hosted an international satellite on HIV/AIDS in Africa: Building North-South Partnerships

On September 19<sup>th</sup>, 2004 the satellite covered areas such as:

Clinical/Medical Perspectives: Similarities, Differences and Opportunities for Collaboration  
Session Chair: Joan Holloway, HRSA

- Eunice Garanganga, Zimbabwe
- Lydia Mpanga, South Africa
- Carla Alexander, USA

Psychosocial and Spiritual Support: Similarities, Differences and Opportunities for Collaboration  
Session Chair: Paul Lucas, The GlaxoSmithKline Foundation

- Sekagya Yahaya Hills, Uganda
- Bob Cardinal, Canada
- Helen Schietinger, USA

Children's Issues: Similarities, Differences and Opportunities for Collaboration  
Session Chair: Donald Schumacher, NHPCO

- Zipporah Ali, Nairobi
- Stephen Gitonga, Kenya
- Nancy Hutton, USA
- Joan Marston, South-Africa

Public Health and Resources: Twinning - What Have We Learned?

Session Chair: Olivia Dix, The Diana Princess of Wales Memorial Fund

- Liz Gwyther, South Africa
- Michael O'Connor, Canada
- Phil DiSorbo, USA
- Becky MacDonald, USA

Summary of the Day and Closing Comments

Session Chair: Dr. Bernard Lapointe

- Sambulo Mkwanzani, Zimbabwe
- Peter Selwyn, USA

The opening plenary session was given by Dr. José Pereira and Joseph F. O'Neill.

Satellites like this allow collaboration and networking of international partners to come together.

Please see Appendix B for the meeting notes of this satellite session.

## International Challenge Panel

On October 19, 2009 at the Canadian Hospice Palliative Care Association`s national conference, Voyages in Care and Understanding, Sharon Baxter, Ingrid de Kock and Bernarde Lapointe presented a Challenge Panel titled - **What is our Obligation to Care on the International Front in an Environment Where We are Struggling for Resources at Home?**

Highlight discussions of this challenge panel were:

What can we do on a:

- local program level
- provincial or regional level
- university level
- national level

The challenge panel also gave an overview of first world content versus third world content.

Please click on the links below to view the PowerPoint presentations from this challenge panel.

- [International aid in tough econ. times Winnipeg for web.ppt](#)
  - (presented by Ingrid de Kock)
- [What is our Obligation to Care on the.ppt](#)
  - (presented by Bernarde Lapointe)
- [WPCA Challenge panel monday oct 19th 2009.ppt](#)
  - (presented by Sharon Baxter)

# Worldwide Hospice Palliative Care Alliance

## **Media Toolkit**

The mission of the Worldwide Palliative Care Alliance (WHPCA) is to promote universal access to affordable quality palliative care through the support of regional and national hospice and palliative care organizations.

The WHPCA works to promote the development of hospice and palliative care for people living with life-limiting illness.

World Hospice and Palliative Care Day (World Day), a sub group of the Worldwide Palliative Care Alliance, provides an opportunity to raise awareness of hospice and palliative care services and related issues in the local, regional, national and international media by creating a media toolkit.

There are numerous ways in which this opportunity can be realized, and the purpose of this toolkit is to suggest some different approaches and guidelines that you might like to consider.

The toolkit is divided into two sections

Section 1: How the media works and

Section 2: Documents for external use

The media toolkit was compiled by Help the Hospices. Please go to [www.helpthehospices.org.uk](http://www.helpthehospices.org.uk) for more information.

## **Advocacy Toolkit**

In March 2003 many national hospice palliative care associations came together for the 1st Global Summit of National Hospice and Palliative Care Association in The Hague, Netherlands. We listened and learned from one another and this led to the 2nd Global Summit in Seoul, Korea. This subsequently led to the Korea declaration (see [www.hpcassociations.net](http://www.hpcassociations.net)). To prepare for this summit Help the Hospices facilitated an advocacy committee to assist in preparing the content and agenda. Not surprisingly, one of the key issues we heard repeatedly is access – access to both hospice and palliative care programs and services and access to essential medicines including morphine. We heard that access is an issue for both developed and developing countries. Advocacy becomes a key response to the access issue. Help the Hospices took the lead to help prepare this advocacy document using resources and references from around the world. We hope it is a good summary and that it assists you in your own countries with this much-needed advocacy.

The advocacy toolkit covers:

- Introduction to Advocacy
- Advocacy Tools
- Key Guidelines on Palliative Care

Please go to <http://www.thewpca.org/search/?q=advocacy+kit> to view the Advocacy Toolkit.

## Twining

In March 2006, the African Palliative Care Association (APCA) collaborated with the Canadian Hospice Palliative Care Association (CHPCA) together on a twinning project entitled “Empowering Men in five Sub-Saharan African Countries as Care Givers Through Training and Education to Enhance the Scale-Up of Palliative Care for People Living With HIV/AIDS in the Region”.

The overall objective of the project was to empower men from the five target countries participating in this project with the knowledge and skills related to hospice palliative care as they take on the role of primary caregivers for people living with HIV/AIDS. Hospice palliative care associations working in Sub-Saharan Africa have recognized that there is an ever-increasing need to train men as caregivers, especially when female members of the family unit or community are living with or dying from HIV/AIDS.

In Africa, the focus on HIV/AIDS prevention, care and treatment has concentrated on women based on their traditional role as caregivers for the sick. However, African men are increasingly volunteering with community caregiver programs in many countries and this provides an opportunity for extending to them crucial knowledge and skills in the area of palliative care. In Uganda, for example, community-based organizations for men living with HIV/AIDS have been established and are looking for any available training opportunities in caregiving. In Hospice Africa Uganda, about 60% of trained community volunteers are men.

The twinning project was subdivided into three sections

- A Trainers Manual
- A Trainers Guide
- PowerPoint

If you are interested in finding out more about this project, please contact [info@chpca.net](mailto:info@chpca.net).

## **HIV/AIDS Twinning Partnerships:**

Please see below for name and links of other twinning partnerships.

### **1. The HIV/AIDS Twinning Center – American International Health Alliance**

<http://www.twinningagainstaids.org/>

The 12 countries with twinning partnerships are listed below, eleven of which are in sub-Saharan Africa.

- Botswana
- Cote d'Ivoire
- Ethiopia
- Kenya
- Mozambique
- Namibia
- Nigeria
- Russia
- South Africa
- Tanzania
- Uganda
- Zambia

### **2. African Palliative Care Association**

<http://www.apca.org.ug/index.php>

Established formal mentoring programs in five African countries, they are:

- Kenya
- Mozambique
- Tanzania
- Uganda
- Zambia

### **3. Interagency Coalition on AIDS and Development**

<http://www.icad-cisd.com/content/en/twinning>

Includes Twinning events, resources, websites and listservs.

### **4. International Twinning and Partnership for Development – CEMR**

<http://int.twinning.org/>

### **5. Health Canada - The 'How-To' Guide to Hospice Palliative Care Twinning Projects**

<http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2009-twinning-jumelage/index-eng.php>

## Appendix A

### International Hospice Palliative Care Resource Commons Brochure

# ONLINE International Hospice Palliative Care Resource Commons

Twining ▶

Advocacy ▶

HIV/AIDS ▶

World Hospice Palliative Care Day ▶

Media ▶



Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

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Please visit [www.chpca.net](http://www.chpca.net) for more details and watch for further announcements

Production of this flyer has been made possible through a financial contribution from Health Canada

The views expressed herein do not necessarily represent the view of the federal government.

## Appendix B

### **HIV/AIDS in Africa: Building North-South Partnerships**

**Sunday, September, 19, 2004 - Montreal, Canada**

#### **Meeting Notes**

##### **Overview:**

This all-day seminar will present strategies for addressing HIV/AIDS palliative care in sub-Saharan Africa.

Presenters from North America, the United Kingdom and Sub-Saharan Africa focused on the challenges, the differences and the convergences of palliative care delivery in the South and the North and how partnerships can and could enrich the delivery of quality end-of life care for People Living with HIV/AIDS. During the afternoon sessions, particular attention was paid to the unique needs of children infected with and affected by HIV and a specific panel discussion looked at 'twinning' as a specific example of partnership between services and hospices in the north and the south. That session also presented resources for and benefits of North-South twinning.

This seminar was designed to meet the needs of professional and volunteer caregivers delivering palliative care in the North or the South and of programs or services that are actively involved in partnerships or are wishing to embark in such a collaborative effort. Participants, many of whom traveled from Sub-Saharan Africa, were encouraged to actively participate in the discussions.

**Partners:** United States Department of Health and Human Services, Health Resource and Services Administration (HRSA)  
National Hospice Palliative Care Organization (NHPCO)  
Diana, Princess of Wales Memorial Fund  
The GlaxoSmithKline Foundation  
Canadian Hospice Palliative Care Association (CHPCA)

##### **Satellite Venue:**

Montreal Convention Centre (Palais des congrès)  
201 Viger Street West  
Montreal, Quebec  
CANADA

##### **Chair for the Day: Dr. Bernard Lapointe**

Dr. Bernard Lapointe opened the meeting and welcomed everyone to Montreal. This one day satellite took place in conjunction with the 15<sup>th</sup> International Congress on Care of the Terminally Ill, a bi-annual conference which in 2004 attracted more than 1,350 delegates from 34 countries.

Mr. Robert Cardinal, a First Nations Elder was invited to open the meeting with a prayer of thanksgiving.



## **Opening remarks from the some of the Partners:**

### *Olivia Dix, Diana, Princess of Wales Memorial Fund*

The Diana, Princess of Wales Memorial Fund is a private charitable foundation based in the United Kingdom. One of the programs supported by the Fund is palliative care in Sub-Saharan Africa. The program began in 2001 and has become a passion for the staff at the Fund. Ms. Dix reported that the employees of the Fund have a great respect for those working in palliative care and have been touched in a positive way by their spirit.

### *Karen Chow, The GlaxoSmithKline Foundation*

The GlaxoSmithKline Foundation was created in 1997 by the employees of GlaxoSmithKline Inc. The employees were guided by the conviction of wanting to make an impact through corporate and personal philanthropy. The employees chose hospice palliative care as their cause of choice. The major achievement of the Foundation is the Living Lessons social awareness campaign which has been developed in partnership with the Canadian Hospice Palliative Care Association.

### *Don Schumacher, National Hospice Palliative Care Organization*

The National Hospice Palliative Care Organization has noticed a marked increase in interest among US hospices in partnering with groups in Sub-Saharan Africa. The Organization has been working on a strategic plan to increase partnerships over the next 5 to 10 years. The Organization is also pleased to be partnering with The Foundation for Hospices in Sub-Saharan Africa (FHSSA).

## **Plenary**

### **Plenary #1 : Opening Plenary**

**Session Chair:** **Dr. Bernard Lapointe**, Chief of Palliative Care, Sir Mortimer B. Davis Jewish General Hospital, Montreal

**Speakers:** **Dr. Jose Pereira**, Vice-President, Canadian Hospice Palliative Care Association  
(*Speaking Notes: Appendix A*)

**Julie Chitty**, HIV/AIDS Palliative Care Advisor, Office of the US Global AIDS Coordinator (*Speaking Notes: Appendix B*)

### **Plenary #2 : Clinical/Medical Perspectives: Similarities, Differences and Opportunities for Collaboration**

**Session Chair:** **Sharon Baxter**, Executive Director, Canadian Hospice Palliative Care Association

**Speakers:** **Eunice Garanganga**, Clinical and Technical Adviser, Hospice Association of Zimbabwe (HOSPAZ), Team member for WHO Palliative Care Initiative in Zimbabwe, Board of Directors for African Palliative Care Association (APCA)  
(*Speaking Notes: Appendix C*)

**Dr. Lydia Mpanga Sebuyira**, Director of Education, Hospice Africa Uganda. Formerly WHO/Diana Fund Consultant to Country Palliative

Care Teams, Tanzania and Zimbabwe. President of the Palliative Care Association of Uganda. Member of the Royal College of Physicians(UK)  
(*Speaking Notes: Appendix D*)

**Dr. Carla Alexander**, Assistant Professor of Medicine at the University of Maryland School of Medicine and in the Institute of Human Virology. Director of Palliative Care for the University of Maryland Medical Center in Baltimore, Maryland, US. Medical Director, National Hospice and Palliative Care Organization (*Speaking Notes: Appendix E*)

### **Plenary #3 : Psychosocial and Spiritual Support: Similarities, Differences and Opportunities for Collaboration**

**Session Chair:** Karen Chow, Vice-President, The GlaxoSmithKline Foundation

**Speakers:** **Dr. Sekagya Yahaya Hills**, African Traditional Healer, Representative Director of PROMETRA International, Head of Department of Traditional Medicine, Luwero University (Uganda), Member Council of Directors, Scientific and Legal Committee PROMETRA INTERNATIONAL (*Speaking Notes: Appendix F*)

**Bob Cardinal**, First Nations Elder working in Edmonton, Alberta, Canada

*Notes:* More than 11 years ago a group of First Nations Elders was approached by medical staff in Edmonton who asked if they would be willing to perform the Sweetgrass Ceremony within a hospital setting. The Elders agreed but would need to recruit helpers. Bob Cardinal is one of those helpers. At first there were many challenges due to misunderstandings and misconceptions of First Nations people. Today it is more widely accepted. When patients and families approach Bob they approach with a gift of tobacco. Acceptance of the gift of tobacco is a commitment to the Creator and to the family. Bob feels that it is an honour to be present with a family at the point of death. The Sweetgrass is braided three ways to signify the Body, Mind and Spirit. At death there are many emotions. The Sweetgrass ceremony can help people prepare and gain strength. For Bob it has been a blessing to be able to share this in the hospital setting and nurses are now starting to refer cases to him.

**Helen Schietinger**, AIDS Certified Registered Nurse with a masters degree in counseling, has worked in HIV/AIDS since 1981. She developed the first residential program for people with AIDS in the U.S. In 1988, she joined the Global Programme on AIDS at WHO as the Technical Officer for Care and Support, promoting inclusion of home- and community-based care, symptom management, palliative care, and traditional medicine into services provided through National AIDS Control Programmes. She is now an HIV consultant in the U.S. In 2003 she co-edited *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS*.

#### **Plenary #4 : Children’s Issues: Similarities, Differences and Opportunities for Collaboration**

**Session Chair:** Donald Schumacher, National Hospice Palliative Care Organization

**Speakers:** Dr. Zipporah Ali, Nairobi Hospice, Kenya  
(Speaking Notes: Appendix G)

**Dr. Nancy Hutton**, Associate Professor of Pediatrics at Johns Hopkins School of Medicine and directs the Pediatric & Adolescent HIV/AIDS Program there. As a Faculty Scholar in the Project on Death in America, she became medical director of Harriet Lane Compassionate Care, the palliative care program of the Johns Hopkins Children’s Center, and pediatric medical director for Maryland Community Hospice. She is active in international efforts to integrate palliative care with antiretroviral therapy for children with HIV.  
(Speaking Notes: Appendix H)

**Joan Marston**, Professional Nurse and Nurse Educator. Advocacy Officer for the Hospice Palliative Care Association of South Africa. Founder of The St Nicholas Children’s Hospice in Bloemfontein. Initiated the development of the first paediatric palliative care curriculum for professional members of the multi-disciplinary team. Chairperson of the South African national task team for paediatric palliative care, to develop paediatric palliative care throughout the country  
(Speaking Notes: Appendix I)

#### **Plenary #5 : Public Health and Resources: Twinning What Have We Learned**

**Session Chair:** Olivia Dix, Executive Director, The Diana Princess of Wales Memorial Fund

**Speakers:** Dr. Liz Gwyther, Chief Executive Officer, St Luke’s Hospice. Is a member of the education sub-committee of Hospice Association of South Africa (HASA) and is a member of the HASA Board.  
(Speaking Notes: Appendix J)

**Michael O’Connor**, Executive Director of the Interagency Coalition on AIDS and Development (ICAD). He provides expertise to ICAD’s capacity building programming for members and leadership in policy research and advocacy on HIV/AIDS and development issues.  
(Speaking Notes: Appendix K)

**Phil DiSorbo**, Executive Director, The Community Hospice  
(Speaking Notes: Appendix L)

*Note: Becky Macdonald (USA) was scheduled to speak at this satellite however was unable to attend.*

**Comments:** How can an organization “scale-up” our twinning processes? How can we connect in our own country so that we don’t overlap with other work?

Liz Gwyther indicated that models are available. Organizations who have done this before know what does and doesn't work and are willing to share this information. Many national associations have the resources in place to assist with "scaling-up" twinning. Groups need to look outside the hospice movement. It may be possible to get institutions (hospitals) to take part in twinning.

Are there any threats or detriments to twinning?

Phil DiSorbo indicated that there can be some challenges when exploring the idea of twinning. It is important for groups to work diligently in order to develop meaningful partnerships.

## **Plenary #6 : Summary of Day and Closing Comments**

**Session Chair:** **Dr. Bernard Lapointe**, Chief of Palliative Care, Sir Mortimer B. Davis Jewish General Hospital, Montreal

**Speakers:** **Sambulo Mkwanzani**, Registered Public Health Nurse, Zimbabwe. Sambulo trained and worked in UK for 24 years as a community practice teacher working with inner-city communities in London. Return home to Zimbabwe in 1994. Worked with the Ministry of Health and Child Welfare to implement palliative care under the cancer control programme. Training was carried out in all provinces until funds ran out. Sambulo then joined Island Hospice as the Training Manager, developing training and awareness programs for poorly resourced areas.

### ***Comments:***

- As this satellite began it became clear there is commitment towards Sub-Saharan Africa. It is also very encouraging to see that the commitment is holistic and not just prevention.
- Clinical and medical perspectives – this is a difficult time. There is a huge lack of resources despite excellent staff.
- It was interesting to hear that what is going on in America among marginalized communities is similar to the African experience.
- Among the opportunities for collaboration we need to help each other with information and technical assistance (IT skills and documentation)
- We can learn a lot from evidence based practice
- It is good to see that we are beginning to address the psychosocial and spiritual issues of those who are dying.
- Children's issues: there are a lot of issues that adults have to address in caring for children. We need to challenge ourselves to give more credit to children when talking about their own death or the death of family members.
- Twinning – strong partnerships strengthen the leadership in grass roots organizations.
- Benefited from field visits to other hospices

**Dr. Peter Selwyn**, Professor of Family Medicine and Internal Medicine, and Chairman of the Department of Family Medicine and Community Health at Montefiore Medical Center and Albert Einstein College of Medicine in the Bronx, New York. He is also Director of the HIV Palliative Care Project and the hospital-wide Palliative Care Service at Montefiore Medical Center.

***Comments:***

- An enormous amount of wisdom, experience, compassion and clarity was expressed during this satellite.
- Main issues noted:
  - Beyond then clinical and public health issues is the reality of social injustice and inequity. 90% of those living with HIV live in developing countries yet 90% of those who receive care for HIV live in first world countries.
  - Seeing people suffering from HIV who then are put onto an ARV regimen - and then to see their quality of life improve is very encouraging.
  - Not only in the North-South axis, but all HIV care providers have a lot to learn from palliative care providers
  - We need to work better on bridging the gap between HIV care providers and hospice palliative care providers. It is significant that of all the posters presented at this conference only one deals with HIV and palliative care. At the World AIDS Conference this past summer of the 1,000's of abstracts and workshops only 20 were on the topic of palliative care. Both communities need to work on this relationship and not be separated into two separate domains.

**Closing Comments:**

Dr. Bernard Lapointe closed the meeting and thanked the speakers for their wisdom and comments. Dr. Lapointe also thanked those who attended the satellite session and challenged them to take what they had learned back to their home communities.

Sincere appreciation was also expressed to the Partners who hosted this event:

- United States Department of Health and Human Services, Health Resource and Services Administration (HRSA)
- National Hospice Palliative Care Organization (NHPCO)
- Diana, Princess of Wales Memorial Fund
- The GlaxoSmithKline Foundation
- Canadian Hospice Palliative Care Association (CHPCA)