Funding Hospice and Palliative Care Internationally: The Funder’s Perspective

Mary V. Callaway
Director, International Palliative Care Initiative
Open Society Institute
EAPC Vienna Congress May 2009
Outline

1. Mapping of donors
2. OSI’s International Palliative Care Initiative
3. What do donors’ want?
Mapping of Donors

Michael Wright
International Observatory on End of Life Care
Lancaster University

http://www.eolc-observatory
Objectives

- To create an easily accessible web-based database of national and international foundations and agencies that provide funding for hospice and palliative care activities in developing countries.

- To serve as a resource for donors interested in funding palliative care and palliative care programs seeking funding.
## Typology of Donors

<table>
<thead>
<tr>
<th>Type</th>
<th>Donors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multilateral</td>
<td>World Bank, United Nations</td>
</tr>
<tr>
<td>Bilateral</td>
<td>USAID, Irish AID</td>
</tr>
<tr>
<td>Humanitarian</td>
<td>Li Ka Shing Foundation, Red Cross</td>
</tr>
<tr>
<td>Faith-based</td>
<td>American Jewish Joint Distribution Committee, Scottish Catholic International Aid Fund</td>
</tr>
</tbody>
</table>
## Typology of Donors

<table>
<thead>
<tr>
<th>Category</th>
<th>Donors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Business</td>
<td>AngloGold Ashanti, Rolls Royce India</td>
</tr>
<tr>
<td>Hospice Support</td>
<td>Friends of Swaziland Hospice, St Petersburg Healthcare Trust</td>
</tr>
<tr>
<td>Nat’l or Int’l Associations</td>
<td>International Association of Hospice and Palliative Care, European Society of Medical Oncology, Help the Hospices</td>
</tr>
<tr>
<td>Other</td>
<td>European School of Oncology, North South Development Trust</td>
</tr>
</tbody>
</table>
Survey Contains

- name of organization, website
- name of the director, contact details
- countries/regions where they fund
- funding range (average size and duration of grant)
- funding cycle
- eligibility criteria, selection process
- monitoring and evaluation procedure
- future funding plans and commitments.
Overview of Donors

- **program area**
  - service development
  - education, fellowships, travel grants
  - disease categories (cancer, AIDS, Parkinson’s Disease, lung disease, heart disease)
  - population focus (pediatrics, geriatrics, adolescents, adults)
## Donors by Region

<table>
<thead>
<tr>
<th></th>
<th>CEE/ CIS</th>
<th>Africa</th>
<th>CSE Asia</th>
<th>Latin America, Caribbean</th>
<th>Middle East</th>
<th>India</th>
<th>China</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Multilateral</strong></td>
<td>6</td>
<td>6</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Bilateral</strong></td>
<td>14</td>
<td>19</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td><strong>Humanitarian</strong></td>
<td>52</td>
<td>54</td>
<td>30</td>
<td>4</td>
<td>4</td>
<td>14</td>
<td>3</td>
</tr>
<tr>
<td><strong>Faith based</strong></td>
<td>29</td>
<td>27</td>
<td>16</td>
<td>4</td>
<td>3</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td><strong>Business</strong></td>
<td>18</td>
<td>21</td>
<td>12</td>
<td>3</td>
<td>2</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td><strong>Hospice support</strong></td>
<td>17</td>
<td>9</td>
<td>5</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Natl Intl Assoc</strong></td>
<td>14</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>7</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>157</td>
<td>141</td>
<td>76</td>
<td>22</td>
<td>19</td>
<td>43</td>
<td>5</td>
</tr>
</tbody>
</table>
A review of donor organisations that support palliative care development in five world regions

A report prepared for the Open Society Institute

Michael Wright, Thomas Lynch, David Clark

International Observatory on End of Life Care
Lancaster, 2008
Open Society Institute’s International Palliative Care Initiative (IPCI)

Kathleen M. Foley, M.D. Medical Director
Mary V. Callaway, Director
Kiera Hepford, Program Coordinator
Rebekah Chang, Program Assistant
Soros Network: Public Health Program

- Palliative Care
- Harm Reduction
- Sexual Health and Rights
- Law and Health
- Public Health Watch
- Health Media
- Health Budget Monitoring
- Access to Essential Medicines
- Mental Health Initiative
- Global Fund
International Palliative Care Initiative (IPCI)

- serves as a catalyst for the integration of palliative care into national health care plans, programs, and systems of care in developing countries around the world.
- IPCI also serves as a resource to an international network of individuals and organizations committed to improving care for patients with life-limiting illness and their families.
IPCI

- Geographic Focus
  - Central and Eastern Europe
  - Central Asia
  - West, East, Sub-Saharan, South Africa
  - Southeast Asia
Policy

-- Palliative care included and implemented in national health plans, policies, legislation, regulations, and licensing
-- Funding/education, service delivery

Drug Availability
-- Opioids & essential meds
-- Import quota
-- Cost
-- Prescribing
-- Distribution
-- Dispensing
-- Administration (pharma, Drug regulators, law enforcement agents)

Education
-- Public
-- Policy makers
-- Media
-- Health professionals

Implementation
-- Standards, Guidelines
-- Service delivery across public and private systems

Stjernsward, Ferris
WHO Public Health Model
Solicited Applications

- Capacity Building
  - Regional Palliative Care Associations: APCA, EAPC, APHN, LAPC—IAHPC
  - Palliative Care in Cancer, HIV/AIDS Hospitals
  - Resource Training Centers: Romania, Hungary, Poland, Mongolia, Singapore, Vietnam

- Advocacy: cancer, HIV/AIDS, neurodegenerative diseases, geriatrics, pediatrics, prisoners

- Donors: WHO, USAID, IAEA, INCTR, Global Fund, Diana Fund, True Colors Trust, Elton John Foundation
International Palliative Care Initiative

1. Integrate palliative care into national health care plans, policies, standards, and across delivery systems (Ukraine, Moldova, Georgia)

2. Integrate palliative care into medical and nursing education (Tajikistan, Kenya, Tanzania)

3. Increase advocacy, public awareness
Health and Human Rights

A Resource Guide for the
Open Society Institute and
Soros Foundations Network

Now we have the responsibility to move forward by recognizing that true interdependence and real interconnectedness requires that we—especially health and human rights—advance together.

—Jonathan Mann (1947-1999)

Palliative Care and Human Rights: A Resource Guide

“You must matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die.”

Sara Grey Saunders, founder of the modern Hospice movement
"Please, do not make us suffer anymore......."

Access to Pain Treatment as a Human Right

Human Rights Watch—countries could improve access to pain medications by addressing the causes of their poor availability, including the failure to put in place functioning supply and distribution systems; absence of government policies to ensure their availability; insufficient instruction for healthcare workers; excessively strict drug-control regulations; and fear of legal sanctions among healthcare workers.

International Palliative Care Initiative Goals

4. **Increase funding** for palliative care: Global Fund, PEPFAR, USAID, etc.
5. Serve as an **international resource** for palliative care development
6. **Convene** leaders to work collaboratively: health economics, leadership, policy
7. **Ensure availability** of essential drugs for pain and symptom management for adults and children with life-limiting illnesses, especially opioid analgesics
Drug Availability

Opioids & essential palliative medications

Manufacture
Importation
Distribution
Prescribing
Dispensing
2006 International Pain Policy Fellowship

Dr. Simbo Daisy Amanor-Boadu  
Nigeria

Prof. Snežana Bošnjak  
Serbia

Prof. Rosa Buitrago  
Republic of Panama

Mrs. Nguyen Thi Phuong Cham  
Vietnam

Dr. Henry Ddungu  
Uganda

Dr. Jorge Eisenchlas  
Argentina

Dr. Marta Ximena León  
Colombia

Mr. Gabriel Madiye  
Sierra Leone

Pain & Policy Studies Group  
University of Wisconsin  
October, 2006 Madison, Wisconsin

Supported by the Open Society Institute
International Pain Policy Fellowship Teams
16-20 June 2008

Dr. Zipporah Ali, MD, MPH, Dip. Palliative Care
Kenya Hospices and Palliative Care Association
Dr. Jacinta Nasimiyu Wasiiko
Pharmacy and Poison Board

Kenya

Dr. Adrian Belîi, MD, PhD
Emergency City Hospital, Anaesthesiology and Intensive Care

Republic of Moldova

Dr. Eva Rossina Duarte Juárez, MD
Instituto de Cancerología, Palliative Care Unit
Lic. Ana Lucia Arango Espigares
Ministry of Public Health and Social Assistance, Technical & Regulatory Affairs

Guatemala

Dr. Pati Dzotsenidze, MD
P. Sarajishvili Institute of Neurology & Neurosurgery
Mr. Mikheil Pavliashvili
Health and Social Programs Agency

Georgia

Dr. Hrant Karapetyan, MD, PhD
Armenian Pain Control & Palliative Care Association, “Vahan” Foundation
Dr. Irina Kazaryan, PharmD, PhD, MSc
National Institute of Health, Department of Pharmacy

Republic of Armenia

Dr. Bishnu Dutta Paudel, MBBS, MD
Bir Hospital – Ministry of Health of Nepal
Mr. Radha Raman Prasad Teli
Ministry of Health & Population, Drug Administration

Nepal

Dr. Margaret Dingle Spence, BSc, MBBS, Dip. Pall.Med., FRCR
Hope Institute
Mrs. Verna Walker-Edwards, BSc. Pharmacy
Ministry of Health, Dangerous Drugs

Jamaica

Fellowship funded by:
Open Society Institute
International Palliative Care Initiative
Where’s the money?
difficulty finding funding?
What to do when you go home?

- Identify donors working in your country
- Look for donors that support hospice, health care, education, policy, community development, elderly, pediatrics
- Community based or faith based organizations
- Send letters of intent or respond to requests for applications
Making the Case to Donors

- Who are you and why are you qualified to lead the project? Include your cv

- Who is your organization? When was it created and what does it do? Provide the contact information.
Making the Case to Donors

- Background: Why is this project needed?
  - Give the numbers of patients dying from cancer, AIDS in your country
  - Describe where patients are dying (at home, in hospital)
Making the Case to Donors

- Describe the unrelieved pain and other symptoms from life limiting illness such as cancer, AIDS, neurodegenerative disease in your country.

- Describe the barriers to opioid availability (legal, social, professional, public).
Making the Case to Donors

- What is your organization’s mission, goals, and objectives?
- What is the project you want to do?
- How are you going to do it? What steps are you going to take? Include a timeline.
Making the Case for Donors

- **Budget**: how much money do you need and what are you going to spend it on. Be specific.

- **Who will work on the project?** Give names and brief biosketch for each person to be supported by the grant you are requesting.
Making the Case for Donors

- How long will the project take? Month, year(s)

- How will you know if your project is successful? Change in drug availability, knowledge of policy makers, health care providers, the public
Making the Case for Donors

- Send a copy of your country national palliative care plan and/or strategy

- Send a copy of the workshop program and a list of all the participants
Where’s the Money?

- African Palliative Care Association
- American International Health Alliance
- Anglo Gold
- AUSAID
- BESO (British Executive Services Overseas)
- Bread for the World
- CARE International
- Catholic Relief Services
- Catholic Organization for Relief and Development (CORDAID)
- CIDA
- Diana, Princess of Wales Fund
- DFID
- Elton John Foundation
- Foundation for Hospices in Sub-Saharan Africa
- Global Fund for AIDS, TB & Mal
Where’s the Money?

- Help the Hospices National Hospice and Palliative Care Organization
- Hope for Hospices
- International Association of Hospice and Palliative Care
- Irish AID
- National Cancer Institute--US
- Open Society Institute
- PEPFAR, President’s Emergency Plan for AIDS Relief
- UK Forum for Hospice and Palliative Care Worldwide
- UNICEF
- US Embassy
- World Bank
- Worldwide Alliance for Hospice and Palliative Care
Where’s the money?

- Participate in World Hospice and Palliative Care Day
- Sponsor fundraising events for your organization and/or a specific project
- Make presentations at church or in social clubs about your organization and projects to raise public awareness
- Accept in-kind donations
Making the Case for Donors

- Include letters of support from your national or regional associations

- One week after sending, call or email to follow-up

- Don’t give up!
Once you have support

- Communicate frequently with your donors
- Invite to fundraisers or events
- Send copies of media coverage or progress reports
- Acknowledge in media interviews, publications
- THANK THEM AGAIN, AND AGAIN!
Thank You!

Mary Callaway
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