

## IAHPC News On-Line

### Hospice & Palliative Care News & Information

#### International Association for Hospice and Palliative Care (IAHPC)

William Farr, PhD, MD - Editor  
Liliana De Lima, MHA - Coordinator  
Anne Laidlaw - Layout and Distribution

Dear Members and Colleagues:

The March edition of our newsletter is now on our website at URL:

<http://www.hospicecare.com/news/11/03/>

Please find below an abbreviated version.

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Regards,

Roberto Wenk, MD, Chair  
William Farr, PhD, MD, Vice-Chair and Editor

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### Message from the Chair and Executive Director

Dear readers:

This month, we have important announcements which include changes in our board of directors.

**1. Governance:** As many of you are aware, we recently completed the election of board members and are proud to announce the following new members to the board for the term 2011 – 2013:

- **Fraser Black, MD** (Canada) is the Medical Director of Victoria Hospice Society and Associate Director of the International Network for Cancer Treatment and Research (INCTR) Palliative Care Access (PAX) program
- **Yvonne Luxford, PhD** (Australia) is the Chief Executive Officer of Palliative Care Australia.
- **Lukas Radbruch, MD** (Germany) is the Chair of Palliative Medicine and Director of the Department of Palliative Medicine, University Hospital Bonn, Director of the Centre of Palliative Medicine, Malteser Hospital.

We welcome these extraordinary leaders in palliative care to our board and look forward to their participation as directors of our organization.

Three of our current board members were re-elected to the Board:

- **Eduardo Bruera, MD** (USA) is the Chair of the Department of Palliative Care and Rehabilitation Medicine in the



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Division of Cancer Medicine at the University of Texas MD Anderson Cancer Center in Houston.

- **Frank Ferris, MD (USA)** is the Director of International Programs at San Diego Hospice and Institute of Palliative Medicine.
- **Peter Hudson, RN, PhD.** (Australia) Director, Centre for Palliative Care, St Vincent's & Collaborative Centre of The University of Melbourne....

**2. Pallipedia:** We are happy to announce that Pallipedia, our Online Dictionary, now contains 775 terms and 881 definitions. It has grown and usage indicates that it has become a useful resource for the palliative care community. To visit Pallipedia, click on <http://www.pallipedia.org/>

**3. Workshop in Ukraine:** Later this month IAHPC is co-organizing with the European Association for Palliative Care (EAPC) and the Ukrainian League of Palliative and Hospice Care (ULPHC) a workshop in Kiev, to improve availability of, and accessibility to, opioids in the country. We look forward to this initiative and the action plan that will result after the discussions. This workshop is funded by the Open Society Foundations. We are very grateful for their trust and support as we work on this initiative.

**4. International Narcotics Control Board:** The INCB has released its 2010 annual report which includes a special report titled Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes. We invite you to look at this publication and use it to advocate for improved availability and accessibility of opioids in your country. To read the report, click on [http://www.incb.org/incb/en/annual\\_report.html](http://www.incb.org/incb/en/annual_report.html)

Until next month,

Roberto Wenk, MD, Chair Board of Directors  
Liliana De Lima, MHA, Executive Director

## Updates from two IAHPC Board Members – India

### Palliative Care for Children in a Resource Poor Setting, an Indian initiative

by Dr. Gayatri Palat\*



Today, a child diagnosed with cancer in a developed country has an 80% chance of being cured. Unfortunately, this is not true in India where 75,000 children with recorded cancers each year have a survival rate of less than 20%. Furthermore, of the estimated 2.5 million people in India living with HIV/AIDS, 70,000 are children under the age of 15. Less than 0.4% of needy children have access to palliative care programs designed to address their needs.

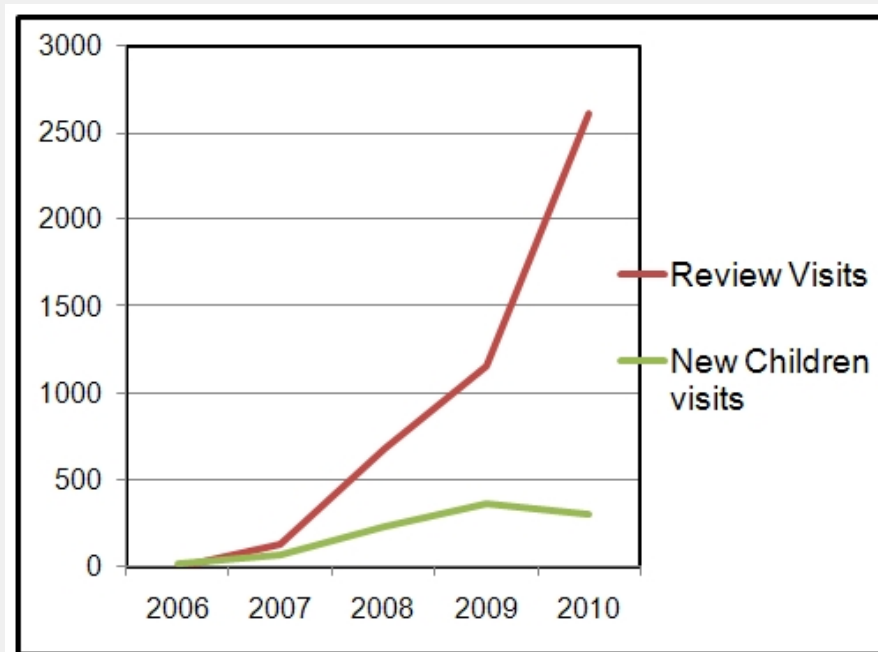
#### Palliative Care for Children in the Mehdi Nawaj Jung (MNJ) Institute of Oncology (MNJIO), Hyderabad

The MNJ Institute of Oncology is a 300 bed tertiary care hospital in the state of Andhra Pradesh, India (population of 65 million). Every year the hospital sees around 1,000 children with cancer....

Enormous suffering results from painful procedures, undesirable symptoms and the emotional trauma of facing potentially

life threatening illnesses.... we realized the dire need for an effective palliative care program for both the children and their families as they confront cancer with all of its physical, psychosocial and spiritual effects....

The primary goal of the program is zero-tolerance of pain beginning at diagnosis. Since the pediatric program was established, there has been a rapid increase in the number of children treated beginning with 69 patient visits in 2006 and 2,922 in 2010 ( Fig 1)....



**Fig 1: Number of Children Seen in Palliative Care**

A few successful outcomes of the program have been:

- almost all children receiving cancer treatment and their families are also receiving adequate symptom control and psychosocial support during curative treatment along with a smooth transition to end of life care if required,
- there has been a significant reduction in the dropout rate during treatment, and
- there is good implementation of procedure-related pain relief protocols....

...we plan to expand it to include all children living with HIV and AIDS and other life threatening illnesses. A fellowship course in pediatric palliative care will start soon to train specialists in the field.

To read the entire report go to <http://www.hospicecare.com/news/11/03/board-member-updates.html>

*\*Dr. Gayatri Palat is the Program Director for PAX India of the International Network for Cancer Treatment and Research (INCTR). She is currently Associate Professor of the Department of Pain and Palliative Medicine in the MNJ Institute of Oncology in Hyderabad. Dr. Palat is also an IAHP board member and her biography may be seen at <http://www.hospicecare.com/Bio/palat.htm>*

## Medical Council of India (MCI) announces post-graduate course in Palliative Medicine

by M.R.Rajagopal MD

A giant step forward: The Medical Council of India, the statutory body that controls medical education in the country, has approved palliative medicine as a medical specialty and initiated steps to start postgraduate courses about the subject...

Doctors working in the field so far have had no academic recognition and could not occupy teaching posts in medical

colleges. We believe this positive step will result in a new generation of medical professionals and hopefully an improvement in the quality of palliative medicine practice in the country...

We look forward to a positive development, but we cannot afford to be complacent. So far, palliative care doctors have come into the field largely because they believe in it and are committed to it. Will the MCI's action lead to a new generation of doctors who practice palliative care just as another job? Will there be a fall in the quality of services? This concern is real, and hence non-government organizations in the field have an important task to demonstrate excellent quality care delivery so that it will serve as a benchmark for teaching institutions.

M.R.Rajagopal MD  
Chairman, Pallium India  
Director, Trivandrum Institute of Palliative Sciences  
S.U.T Hospital, Pattom, Trivandrum 695004  
Kerala, India  
email: [info@palliumindia.org](mailto:info@palliumindia.org) (Office)

Dr. Rajagopal is also an IAHPC board member and his bio may be read at [http://www.hospicecare.com/Bio/mr\\_rajagopal.htm](http://www.hospicecare.com/Bio/mr_rajagopal.htm)

To read the entire report go to <http://www.hospicecare.com/news/11/03/board-member-updates.html#2>

## Two IAHPC Traveling Scholars' Reports

### From Brazil

**Clinical observations during a site visit to the Departments of Palliative Care and Anesthesiology in the *Vrije Universiteit* Medical Center, Amsterdam, The Netherlands**

by Dr Carlos A Albach

The field of palliative care in Brazil has gained importance during the past 20 years with the development and promotion of well-organized services. Today there are about 40 palliative care services (including hospital wards, hospices, outpatient services and reference teams) located mainly in the southeast of Brazil...

I work as a Clinical Oncologist in the Oncology and Hematology Institute of Campo Mourão... This Institute serves as a public referral center for the evaluation and treatment of malignant diseases for about 360 thousand inhabitants, but there is no formally organized palliative care service.... Despite this, palliative care practice in Brazil has no official regulation and is not part of any government or private health policy. Because of this, the study of palliative care by health professionals is limited and far from the ideal...

With this in mind, I participated in a two-month observation/study period in the Palliative Care and Anesthesiology Departments at the *Vrije Universiteit* Medical Centre (VUmc). My main objective was to acquire additional knowledge in evaluation and treatment of patients requiring palliative care....

All ... activities were useful to fulfill my academic goals of learning basic and advanced skills in palliative medicine as well as understanding how an outstanding palliative care service is organized. I now feel much more comfortable as I create a palliative care ward in Brazil committed to the evaluation and treatment of public health patients...

I would like to thank the International Association for Hospice and Palliative Care, the Anesthesiology team and the Palliative Care team at the *Vrije Universiteit* Medical Centre for providing the support that made this clinical observation period possible.

To read the entire report go to <http://www.hospicecare.com/news/11/03/traveling-scholars-reports.html>

### From Africa

by Richard Kaye Mugula, Uganda

The International Association for Hospice and Palliative Care (IAHPC) in conjunction with the African Palliative Care Association (APCA) funded my trip to attend the 18 th International Palliative Care Congress in Montreal Canada during October 2010. I wish to extend my appreciation to IAHPC and my mother organisation (APCA) for their support to attend this important congress....

The purpose of my travel was to share PC information using the minimum dataset for Africa and to learn from other delegates about new developments in palliative care.

My poster presentation 'creating a Palliative Care Minimum Dataset for Africa' was well received. Many people visited the poster, asked questions, sought clarity and shared their experiences with the minimum dataset for PC.

#### **Accomplishments/ Lessons Learnt:**

- One of the key accomplishments was that more than 50 delegates visited my poster. They asked for APCA information, sought information on the PC minimum dataset and shared their experiences with me.
- I was able to improve my presentation and dissemination skills which will enable me to perform better in my organisation as I provide information.
- Through interaction and sharing, I learnt new ways to enhance my work. The wealth of experiences I gained will permit me to incorporate new ideas into some aspects of our work and to improve our interventions....

I learnt many things as highlighted above and I have started to share them with my colleagues at APCA. The lessons learnt about the evaluation of PC programmes are useful and will improve my work. I recommend this congress to other PC practitioners.

Richard Kaye Mugula, Uganda  
Acting Monitoring and Evaluation Manager  
African Palliative Care Association

To read the entire report go to  
<http://www.hospicecare.com/news/11/03/traveling-scholars-reports.html#africa>

## **Article of the Month**

### **Reasons for under-use of prescribed opioid medications by patients in pain**

Lewis ET, Combs A, Trafton JA.

*Pain Medicine* 2010; 11 : 861-871

The fear of overuse, misuse, abuse and addiction in prescribing opioid analgesics in patients with chronic pain is one of the major causes of opioid phobia among physicians and the problems we observe with national regulatory policy regarding pain relief....

Whilst great effort has focused on identifying risk factors for over-using opioids and developing screening tools, less attention has been given to under-use of prescribed opioids despite the evidence that under-use is substantially more frequent....

During the interviews, the authors recognized that while some subjects clearly described over-using opioids, others described various under-use behaviors related to their opioid medication.

Subjects who under-used opioids are those who:

- take less than the dosage allowed by their prescription,
- report inadequate pain relief , or
- report that pain impairs their normal daily activities.

These subjects do not take their opioids, or take them less frequently, or at lower doses, than prescribed even though they report pain alters their QoL.

Problematic under-use of medication was more common than over-use (20% vs 9%). A higher percentage of under-users were female and non-white and reported having more pain but no side effects. They avoided taking opioids even if they had received more than 5 prescriptions in the previous 12 months.

The explanations by patients for under-use of opioids were listed.

#### **Why I choose this article.**

This study does not specifically consider cancer patients experiencing pain however it provides some interesting data.

1. under-use of prescribed opioid medications is more frequent than over-use
2. improved patient-physician communication, appropriate assessment of the intensity of pain as well as its causes (including an evaluation of "TOTAL PAIN") will probably improve outcomes in the oncological and palliative care settings
3. under-use of opioids may be one of the explanations of poor pain control notwithstanding an increase number of prescriptions
4. physicians need to take the time necessary to communicate with patients and their families. This is an important way to understand not only the pain problem but the problems related to analgesic drug prescribing.

Reviewed by Dr. Carla Ripamonti (Italy). Dr. Ripamonti is an IAHP board member and her bio is at [URL insert](#)

To read the entire review go to [http://www.hospicecare.com/Bio/c\\_ripamonti.htm](http://www.hospicecare.com/Bio/c_ripamonti.htm)

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### **Palliative Care Book of the Month**

***A GUIDE TO SYMPTOM RELIEF IN PALLIATIVE CARE 6e*** . Regnard and Dean.

A new edition of this respected handbook.

To read the review go to <http://www.hospicecare.com/news/11/03/reviews.html>

### **Other Reviews**

***SUPPORTIVE CARE FOR THE RENAL PATIENT 2e***. Chambers, Brown and Germain (Eds)

Impressive progress in the application of the principles of palliative care for chronic renal disease.

To read the review go to <http://www.hospicecare.com/news/11/03/reviews.html#1>

**DVD: *LA MAISON DE GARDANNE***. Eric Breitbart

A well-made film of a real hospice at work, French-style.

To read the review go to <http://www.hospicecare.com/news/11/03/reviews.html#2>

**CD: *COUNTRY ROAD. Music for Life's Journey***. Bev Foster, Room 217

Another collection of comforting music for the palliative care setting.

To read the review go to <http://www.hospicecare.com/news/11/03/reviews.html#3>

### Reviews by Dr. Roger Woodruff – February 2011

Dr. Woodruff is a Lifetime Member of the IAHP Board and resides in Australia.  
His full bio is at [http://www.hospicecare.com/Bio/r\\_woodruff.htm](http://www.hospicecare.com/Bio/r_woodruff.htm)

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### Literature on Global issues

*Global Public Health - Retreat from Alma Ata? The WHO's report on Task Shifting to community health workers for AIDS care in poor countries*

C. Campbell a; K. Scott

<http://www.informaworld.com/smpp/content~db=all~content=a916865351~frm=titlelink>

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### ***The Lancet (Letter) - Stronger guidance needed on lifelong care for chronic diseases***

Raoul Andrada Bermejo, Nuggehalli S Prashant, Sanjib K Sharma

<http://www.lancet.com/journals/lancet/article/PIIS0140-6736%2811%2960149-9/fulltext>

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### ***Performance-based financing: just a donor fad or a catalyst towards comprehensive health-care reform?***

Bruno Meessen , Agnès Soucat & Claude Sekabaraga

<http://www.who.int/bulletin/volumes/89/2/10-077339/en/index.html>

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### ***The U.S. Global Health Initiative: A Country Analysis***

From the Kaiser Family Foundation

<http://www.kff.org/globalhealth/8140.cfm>

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### ***The quality of death - Ranking end-of-life care across the world***

From the Economist Intelligence Unit

[http://www.lifebeforedeath.com/pdf/Quality\\_of\\_Death\\_Index\\_Report.pdf](http://www.lifebeforedeath.com/pdf/Quality_of_Death_Index_Report.pdf)

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### ***Quality HIV Care to the End of life***

Richard Harding, Victoria Simms, Eric Krakauer, Liliana DeLima, Julia Downing, Eunice Garanganga, Kimberly Green, Liz Gwyther, and Diederik Lohman

[Clinical Infectious Diseases](#) 2011; [Volume 52](#) (4), 553-554.

<http://cid.oxfordjournals.org/content/52/4/553.full.pdf+html>

## Supportive and Palliative Care Literature

### The National Health Service Evidence – Supportive and Palliative Care

Dear all,

Each month there is a wide range of new items added to the NHS Evidence specialist collection on supportive and palliative care...

Users who cannot easily access the web links below from their email software should access the full list via the link near the top of the home page: <http://www.library.nhs.uk/palliative/> or [See the full lists of new records added each month](#)

Best wishes,

Richard Stevens, Project Manager, NHS Evidence - supportive and palliative care

**To read the entire NHS Evidence - supportive and palliative care - Feb 2011 Bulletin go to**  
<http://www.library.nhs.uk/palliative/ViewResource.aspx?resID=400688&tabID=290>

## Postgraduate Curricula

Dear colleague,

Following suggestions from member countries we are delighted to inform you that the **Recommendations of the EAPC for the development of postgraduate curricula leading to certification in palliative medicine** have now been published in English and Spanish on the EAPC website, go to  
<http://www.eapcnet.eu/Themes/Education/Physiciantaskforce/Recommendations/tabid/691/Default.aspx>

Frank Elsner

Chair of the EAPC task force on medical education

## New and renewing list of members plus donors

We wish to thank all of the following people and institutions for their support during the past month.

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## Announcement

### From the Institute for Palliative Medicine at San Diego Hospice

The **Leadership Development Initiative (LDI)** is for palliative care physicians who wish to develop critical leadership knowledge, skills and behaviors that will help them to advance palliative care capacity locally, nationally and internationally.

The ultimate goal of the LDI is to increase world-wide access to excellent palliative care for those who need it.

Deadline for application is April 30, 2011; stipends are available.

To read the Six focus areas in the LDI curriculum go to  
<http://www.palliativemed.org/Second-LDI-Cohort>

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## Webmaster's Corner

### Website Of The Month

Each month we publish one website that highlights how individuals, organizations, or countries attempt to get their message out about what it is we do in hospice/palliative care.

This month we present **Irish Hospice Foundation** - The Irish Hospice Foundation is a not-for-profit organisation that promotes the hospice philosophy and supports the development of hospice and palliative care.

Website: <http://www.hospice-foundation.ie/>

Read more here: <http://www.hospicecare.com/news/11/03/webmaster.html>

Until next month!

Anne Laidlaw  
 IAHPHC Webmaster

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#### Letters to the editor!

**William Farr, PhD, MD**

Newsletter Editor

May be submitted at: [billfar@hospicecare.com](mailto:billfar@hospicecare.com)

\*\*\*\*Thanks to all contributors to this issue.\*\*\*\*

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