



18 September 2008

Dear friends

We have been sending out these newsletters to you for nearly a year. We realize that we have not always done it well; but we have tried our best within our limitations. It will be good to know what you think of it. For example when Professor David Clark, the director of the International Observatory for End-of-life Care wrote and asked, “*Who sends out these fascinating newsletters?*”, we realized with a shock that we had not even included Pallium India’s contact details in the letter till then. Nevertheless we were pleased that he considered them “fascinating”!

So if you would care to, please take a minute and tell us what you think about this newsletter by email to pallium.india@gmail.com.

Towards the end of this letter, you will find an advertisement in a newspaper that will touch your hearts! But first, here are a few items of news and observations for your attention.

World Palliative Care Day

All round the globe, the palliative care community is getting ready to observe the World Palliative Care Day on Saturday, 11 October 2008. It is a “unified day of action to celebrate and support hospice and palliative care around the world.” To see activities on various parts of the country including India, please visit www.worldday.org. As you will see on that site, the objectives of the World day observance are:

- *To share our vision to increase the availability of hospice and palliative care throughout the world by creating opportunities to speak out about the issues*

- *To raise awareness and understanding of the needs – medical, social, practical, spiritual – of people living with terminal diagnosis and their families.*
- *To raise funds to support and develop hospice and palliative care services around the world.*

In Trivandrum, Kerala, we plan a grand musical program by a celebrated music composer Mr M Jayachandran. The popular cine actor Jayaram will be the guest of honour and famous singers like Jazzy Gift, Vijay Yesudas, Vinith Srinivasan, Chitra Iyer and many others will be performing a three hour program at the University Senate Hall. All the artistes are offering their services free for the cause! Please join us in thanking them and the many people round the world who are helping the cause. Anyone who wishes to participate please email us at pallium.india@gmail.com.

Call for action from International Union Against Cancer:

Global Facts and Figures published by the American Cancer Society say that 12 million people would be diagnosed to have cancer this year. Out of this 7 million would be from economically developing countries. The figures for India will be at least one million this year.

The “International Union Against Cancer (UICC)” estimates that cancer killed almost 8 million people in 2007.

And the saddest part of it all is, the vast majority of them would die without getting proper treatment. And at least half of them would die in pain!

It is in this miserable background that the UICC’s call for action becomes relevant. UICC has come out with “The World Cancer Declaration” which was presented at the World Cancer Congress at Geneva in end of August. It calls on “*governments, international governmental organizations, the international donor community, development agencies, professional organizations, the private sector and all civil society*” among other things, for action to ensure that “*Effective pain control measures will be available universally to all cancer patients in pain*”.

It demands:

Take steps to tackle the many barriers to optimal pain control.

Work with governments to address the over-regulation of pain medicines.

Cooperate with international organizations, including the International Narcotics Control Board

and the World Health Organization, to ensure that global implementation of the UN's international drug control conventions do not unduly interfere with legitimate efforts to advance access to pain medicines for cancer patients in pain”.

The declaration goes on to demand that “*sufficient treatment, rehabilitation and palliative care facilities and well-trained staff are available to meet the physical, social and emotional needs of patients with cancer”.*

To read the full version of the call for action, please go to <http://www.uicc.org/wcd/wcd2008.pdf>

Palliative care and pain relief as human rights: Please sign the declaration.

UICC's call was for action on cancer. But cancer is not the only problem. How about people in pain and suffering from numerous longstanding and disabling diseases? The global organization, “International Association of Hospice and Palliative Care (IAHPC) is collecting signatures for the recognition of palliative care and pain relief as human rights. IAHPC's executive director, Dr Liliana DeLima writes,

“Dear all: You may already be aware of this project we are working on: We are collecting signatures for the recognition of palliative care and pain treatment as human rights.

Every week more than one million people die with chronic and progressive conditions who do not receive any pain treatment. In spite of the advances in palliative care, many doctors, insurance programs, social security systems and national health policies do not cover nor recognize palliative care as a component of care. The vast majority of people die abandoned by the system or in intensive care units, instead of receiving palliative care. Developing countries, where about 80 percent of the population lives, register only about 6% of the total worldwide consumption of morphine, which indicates a huge disparity in access to pain treatment.

Several organizations have joined together and developed a Joint Declaration and Statement of Commitment for the recognition of palliative care and pain treatment as Human Rights. I invite you to sign this Declaration to help us in this effort. The more signatures we are able to collect, the greater chance that we are able to bring this to the attention of the United Nations bodies and governments.

You can see the Declaration in:

http://www.hospicecare.com/resources/pain_pallcare_hr/docs/jdsc.pdf

To sign the Declaration online, please click on

<http://www.hospicecare.com/cgi-script/csFormbuilder/forms/declaration.htm>”

BBC on pain in the developing world.

BBC World Radio broadcast another feature on pain in the developing world on the 25th of August 2008. It featured an interview with Sir Michael Bond, the former president of the International Association for Study of Pain (IASP) and others and helped to bring more international attention to the problem of pain among the marginalized in the world. Thank you BBC, yet again!

Pain, morphine and Uttar Pradesh:

One-sixth of the World's population lives in India. And one-sixth of India's population lives in the state of Uttar Pradesh (UP) - an amazing 166 millions by 2001 census. Hear what a doctor – let us call him Dr X – a retired Professor of Anaesthesiology from Kanpur has to say.

In his role of pain therapist, he has done thousands of interventional procedures – nerve blocks and so on - and has a wealth of experience.

“But interventional procedures will not help in each and every type of pain”, we asked, knowing that he did not have access to oral morphine. “What about the patients who need oral morphine for pain management?”

“I ask them to go out to the market and buy crude opium,” was his reply.

What a paradox! UP is an opium-growing state. They grow it, India exports it and people in developed countries get pain relief. But the people in pain in the poppy-growing area have no access to it! They have to go to the market and illegally find crude opium, which may be of questionable quality. It is no longer sold openly, the way it used to be. It is kept hidden, but it is never hard to find if you go to the market and ask around, Dr X says. With experience you learn to distinguish the good stuff, which feels rather hard, from the poor quality stuff which feels semi-solid.

Mr Piyush Gupta who works with Cancer Aid Society (CAIDS) has a poster where he works. It says, “A hard-core criminal sentenced to death, is still asked to name a last wish. And all efforts

are made to fulfill the wish! Why then, is such a wish denied to the man with advanced cancer, who has to suffer pain for no sin of his!"

Why indeed, we wonder! A combination of ignorance, arrogance and inhuman disregard to suffering of fellow-humans, surely. But how can a cultured society put up with such inhumanity!

An expression of agony from Colombia:

On 12 September 2008, the following ad appeared in a leading newspaper in Colombia. It said:
"Cancer is killing us. Pain is killing me for several days. I have been unable to find injectable morphine in any place. Please Mr Secretary of Health, do not make us suffer any more."

(Thank you, Kathy Kreiter and Fernando Cervero, for bringing this to our attention).

This reminds us of an article that appeared in The Lancet 10 years back titled "A mother in pain" by Ravindra Ghooi and his wife (*Ghooi RB; Ghooi SR; A mother in pain. The Lancet 1998 Nov.14, 352 (9140):1625*). The article described a son's agony when he feared that his mother would have no access to morphine for her cancer pain. He knocked on several doors; none opened. He had to approach the High Court of Delhi which resulted in a landmark judgment which is now a powerful tool in our fight for access to pain relief.

Dear sister in Colombia, we feel your pain. Our hearts ache with yours. We pray and hope that your cry moves a few stony bureaucratic hearts!

Best wishes

The editor

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