



Reaching Out to them
... Together
E-Newsletter

PALLIUM INDIA
CARE BEYOND CURE

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October 10, 2009

Greetings to you on World Palliative Care Day!

Let us start this issue with a difficult question: How would you react if you walked into your five year old child's room and found him hitting himself on the forehead with a brick? An exceptional person was able to turn such a painful occurrence into the creation of something beautiful. You can read about it at the end of this newsletter, but as usual, first we want to give you some good news.

Andhra Pradesh amends and simplifies its narcotic regulations:

One step forward in access to opioids in India. Andhra Pradesh becomes the 14th state of India to amend and simplify its narcotic regulations. This is the consequence of about 10 years of effort. Congratulations, the palliative care team at MNJ Cancer Institute!

The government of India, in 1998, had instructed all states to amend their narcotic regulations, but most did not. The Indian Association of Palliative Care (IAPC) and the Pain and Policy Studies Group (PPSG) at Madison-Wisconsin worked together to effect the change in Andhra Pradesh, but despite two workshops with government officials and professionals, the results had been disappointing. Following the establishment of a palliative care training center at MNJ Institute of Oncology (MNJIO) as a joint initiative of MNJIO, Pallium India, the International Network for Cancer Treatment and Research (INCTR) and the American Cancer

Society, the MNJIO team renewed efforts to bring about change. And we believe the public interest litigation filed by IAPC in the Supreme Court of India helped. Now that the rules have been amended, palliative care centers in Andhra Pradesh can get the required morphine without a complicated licensing process.

Research scholarships in HIV care:

The HIV Research Trust is a charitable foundation that provides financial support for researchers in resource – poor countries working in the field of HIV infection. The support is in the form of Scholarships awarded annually. These are designed for the research worker to travel to another research unit to learn techniques that will be of value when he or she returns. All aspects of research are eligible including clinical care, epidemiology, psychological and societal aspects, basic and applied biology.

The Scholarships, which are usually for a few months duration, cover travel, living expenses and consumables. They are awarded competitively based on a peer-review process. For details visit <http://www.hivresearchtrust.org.uk/>.

We thank Ms Lucy Selman (a long-time friend of India) for bringing this to our attention.

IASP awards:

Martha Maurer from PPSG reminds us about awards from International Association for Study of Pain (IASP). As Martha says, one that might be particularly useful could be the 'Developing Countries Project: Initiatives for improving pain education' which is a \$10,000 grant. The application deadline is February 15, 2010. If you would like the details of the award please visit http://www.iasp-pain.org/AM/Template.cfm?Section=IASP_Developing_Countries_Education_Grant

Bruce Davis Gold Medal

Young Indian doctors, your attention please! It is time to compete for Bruce Davis Gold Medal. The Institute of Palliative Medicine at Kozhikode in Kerala will be conducting a national examination in Palliative medicine to choose the recipient for this year's Bruce Davis gold medal. Those who have appeared (or are appearing) for their final MBBS examination between December 31 December 2006 and 31 December 2010 from any Medical College in India can

appear for the examination. There is no registration fee. Details can be found at <http://bdgm.blogspot.com/>. Those who are interested should go to that page, download the application form and an MCQ and work on it themselves.

The completed questionnaires along with the application forms should reach the Institute of Palliative Medicine, Pain and Palliative Care Society, Medical College, Calicut- 673008, Kerala, India by post before 15 November 2009. Ten top scorers in the screening test will qualify for the final examination to be held at the Institute of Palliative Medicine, Calicut. The selected candidates are entitled to III a/c return fare to Calicut by train and will be provided accommodation at the institute during the final examination in January 2010.

The winner will be awarded the Bruce Davis Gold Medal in Palliative Medicine, a citation and cash award of Rs. 25,000/-

And, about the man behind it, Mr Bruce Davis:

Let us introduce Mr Bruce Davis to those who do not know him – a strong, silent pillar of support for Indian palliative care scene. But wait a minute; it may be the best thing to hear his own account of what he has done, understandably toned down by his modesty.

"I first took an interest in cancer matters following the death of a friend from the disease in the 1950's. Subsequently, in 1966 and 1974 my mother and father also died of cancer. In those days, no special training was given relating to pain relief or palliative care and I found this position quite scandalous in a prosperous country.

In 1967, I set up a Charitable Trust in order to do what I could to promote awareness of the problem in the UK and to provide specialist care for cancer patients. This was and still is a small family Trust, not seeking money from the public but working with other larger charities on occasion.

From small beginnings, through contact with and financial help to National Organisations such as Marie Curie and Cancer Relief (now Macmillan), the Trust grew until it was able to provide in 1979, in conjunction with Cancer Relief, the first dedicated nursing service in Cornwall consisting of 2 trained nurses. Over the course of time, the service has spread nationally into a most effective force for the relief of pain, both physical and mental, for cancer patients and others suffering from terminal illnesses.

Following the great improvement of cancer care in the UK, the Trustees felt that they

should use the expertise that had been gathered in the home environment and try to spread this experience among those overseas who were less fortunately placed.

In the 1990's the Trust carried out initial work, in concert with the Hong Kong Government, in the development of a dedicated nursing service there; nurses were trained alongside our team in Cornwall and at UK Hospices and this co-operative work resulted eventually in the setting up of a Macmillan type home care service. The Trust Nurse Consultant, Val Hunkin, also did considerable work in Nairobi.

In the late 1990's, she was on a visit to India giving workshops with Dr Robert Twycross at Calicut, amongst other venues. On her return to the UK she reported that she had met a most remarkable team in Calicut at the Pain and Palliative Care Society there and we decided to back their endeavours with finance and any other help we could. There followed a meeting between myself and Dr Rajagopal in Mumbai at which I pledged enough financial backing to build a facility consisting of a Hospice and Training Unit, two nurses houses and a building for residential visitors; this is now called the Institute of Palliative Medicine. Much additional support has been given to most of the other projects radiating from the PPCS in Calicut organised through their innovative concept of Neighbourhood Networking....over the years, I have developed an enormous admiration for the work done there and the interest and caring attitude shown by literally thousands of volunteers who are associated with this work.

I have also built up a close relationship with the team of doctors there, particularly Dr Suresh Kumar and Dr Anil Paleri with whom I have spent much time discussing plans for future expansion both by visits and constant e-mails. Dr Rajagopal has moved to Trivandrum, where the Charity Pallium India which he set up, is now based and I work very closely with him in developing his work through his Trust in South Kerala and the wider world. Dr Rajagopal has been my good friend and mentor ever since we met.

The above is a very brief account of how I became involved with the Indian scene, which also includes the Hospice in Vellore and the PPCS in Guwahati, Assam.

Throughout all the time I have been involved with the little input my Trust could give to the enormous problem confronting cancer sufferers in India, I have been inspired by all whom I have met concerned with the task and I have been honoured and my life greatly enriched by working with them. I will continue to do what I can as long as I am physically able."

Dear Bruce, words are inadequate to express the gratitude and love that many of us in India have for you. It has been a privilege a boon to have had the opportunity to work with you. THANK YOU.

New resource center

Dr Frank D. Ferris, MD, (Director, International Programs, Institute for Palliative Medicine at San Diego Hospice, 4311 Third Avenue, San Diego, CA, USA 92103-1407) writes to say, "we have just opened, the International Palliative Care Resource Center, a new website that is designed to be a portal to palliative care resources on the Internet, see <http://www.ipcrc.net/index.php>. We are creating this in collaboration with the Office of International Affairs at the National Cancer Institute, Bethesda, Maryland".

Two recent conferences:

The Lance Armstrong Foundation succeeded in getting major players in the cancer field together at the Livestrong Summit at Dublin in August 2009. Discussions covered all aspects of cancer care including palliative care. More than 65 countries were in attendance, including a strong Indian contingent and several from many developing countries. A generous scholarship program had enabled the attendance of most of the participants from developing countries.

And in September 2009 at Perth, two organizations had a joint conference – Asia Pacific Hospice Palliative Care Network (APHN) and Palliative Care Australia (PCA). It was called "Together 2009!" There were participants from 38 countries. 5% of all the registration fees and a generous contribution from the Australian Government had enabled a bursary program which paid for the expenses for 28 participants from developing countries. And it is so gratifying to find that the citizens of Perth responded warmly to the call from the organizers and took in these participants as guests in their own homes. This reduced costs, and also fostered a spirit of international friendship and care.

The most striking thing about these two events, we feel, is that the Lance Armstrong Foundation and the Australian "Together 2009" team cared enough about people from the developing world. Often it is not easy to see beyond "narrow domestic walls"; but they did! We are reminded of the words of Jan Stjernsward and Sandro Pampallona, "there cannot be one

ideal future to the developed nations and another future for developing nations. It is either a joint future or none.”

Palliative sedation does not hasten death:

Italian researchers evaluating overall survival in a multicenter, observational, nonrandomized trial with two cohorts of hospice patients found palliative sedation therapy did not shorten life when used to relieve refractory symptoms. The investigators enrolled 518 patients. Median survival in the 267 patient palliative sedation cohort was 12 days, and median survival in the group with 251 patients receiving routine hospice care was nine days. Cohorts were matched for age, gender, reason for admission, and Karnofsky performance scores.

<http://annonc.oxfordjournals.org/...>

This is good news. In the face of “intolerable suffering” from “refractory symptoms” in the end of life, (like unrelieved pain, terminal agitation or unrelieved breathlessness etc), palliative sedation – sedation to the point of unconsciousness so that the suffering is relieved - is not only ethically justifiable, but essential. In fact, from what we know today, it would be ethically unjustifiable not to do so. This has nothing to do with euthanasia or mercy killing in which the intention is to end life, because here the intention very clearly is relief of suffering. Yet the thought that he might inadvertently shorten life had deterred physicians and families from providing palliative sedation. Hence the importance of the paper.

Pain relief improves surgical outcome!

Dr Murli Lakhwani is a vascular surgeon from Malaysia. Trained in UK, he worked in UK for some years, and then returned to his home country. Somewhere along the way, he got into palliative care and says, that changed his life. It also changed his surgical work. Very much for the better, he says. We asked him how.

He mentioned several ways in which his surgical work improved. One was simply that he was empowered to treat pain and other suffering. And he started seeing and treating the patient as a whole. But yet another factor that he mentioned is strikingly important. He says, by relieving pain, he was not only relieving the distress for the time being, but was also improving the patient’s compliance to treatment, and actually improving vascularity of the limb.

If you have not had a chance to think about it, here is the mechanism. Lack of blood flow causes pain. Pain causes reflex vasoconstriction, worsening the blood flow further and setting a vicious cycle in motion. In an impending gangrene, if there is some significant collateral blood flow, pain relief may even help to avoid an amputation!

Access and control news from W.H.O:

Please take note of an important piece of information from Access and Control Newsletter No. 4 of September 2009 from the World Health Organization. This year, WHO published the "Guidelines for the Psychosocially Assisted Pharmacological Treatment of Opioid Dependence." We believe this document will help in bringing clarity of thought to doctors who have been afraid to provide pain relief for fear of dependence.

The definition of spirituality at end-of-life

In a letter to the editor published in the Journal of Palliative Medicine from Netherlands (<http://www.liebertonline.com/doi/pdf/10.1089/jpm.2009.0103>), the authors have questioned a definition of spirituality published in the January issue of the journal. In that article, "A Conceptual Analysis of Spirituality at the End of Life," the Canadian authors defined spirituality as a "developmental and conscious process, characterized by two movements of transcendence; either deep within the self or beyond the self." The Dutch writers feel that including transcendence did not resolve the problem of spirituality being an abstract term. They also felt that conscious experience might be problematic for many patients at end-of life-and could exclude patients with mild or more severe cognitive issues.

Well, while the matter is being argued out at an academic level, we wonder whether all the long words are really necessary. May be something that could be simple is being made complicated? Something simple like, spirituality is about the goodness in oneself and around one? That when that goodness is being challenged it causes spiritual pain? And that for spiritual pain, unconditional love is the most powerful therapeutic tool?

Important reminder to all palliative care programs in India:

For the attention of Palliative care programs in the 14 states of India which have simplified their narcotic regulations: please note. In the month of November, you must submit to

Drugs controller of your state the quantity of morphine consumed by your organization and the expected need for the next year.

In Kerala, the Drugs Controller has advised that palliative care units must submit their annual requirements to the advisory panel member of the region, who is to collate all the reports and submit them to the Drugs Controller.

Thank you Dhakshina:

Dhakshina UK, a dance academy based in the United Kingdom held a fund-raising event in London, and Pallium India was the privileged recipient of the proceeds which it shared with a UK charity. We received the cheque during a dance and music extravaganza held at Kochi on 8 August 09. Thank you Dhakshina and thank you Athmaja for getting us in touch with Dhakshina.

World Palliative Care Day in Trivandrum:

The whole world observes World Palliative Care day on the second Saturday of October. Pallium India's Trivandrum Institute of Palliative Sciences (TIPS) is organising a "Kudumbasangamam" (a family get together) for our patients and their families on 10th October 2009 at Cotton Hill School, Trivandrum. School children from seven schools will entertain them with different cultural programs. And patients and families have an opportunity to share their experiences.

Under the leadership of Mr R.S.Sreekumar, the founder of Sukrutham Palliative Care Society, there will be a motorbike rally by volunteers of link centres carrying the message of palliative care. The rally will culminate in Cotton Hill School at 9 AM.

Soorya India festival, reputedly Asia's largest cultural festival in Asia is mega event lasting more than 100 days. Their *bharatanatyam* performance on 10 October 2009 is being dedicated to palliative care.

Rajeswari foundation, our associate, will hold a seminar on palliative care followed by a musical event at Cotton Hill School from 5.30 PM onwards. The Honorable chief minister of Kerala, Sri V.S.Achuthanandan will inaugurate the program. All are invited.

SuperSibs:

Most of those who saw Melanie Goldish in Dublin looking resplendently Indian in a bright green silk sari, wearing a "bindi" on her forehead, and being the life and soul of the party, would not have suspected the pain that she and her boys had gone through. Melanie's elder son Travis was 5 when he was first diagnosed to have cancer and had a bone marrow transplant. He went through the treatment and went back to school, and at the age of 16 got another cancer. The treatment is over and he is now back in high school. He talks as if it was no big deal. "My friends helped with the lessons, though I had to miss school for a while. I shall be alright!", he says.

But this story is not really about Melanie or Travis. It is more about Spencer, Travis's younger brother, just one year younger than Travis. Travis was 5; going through the treatment, and Spencer was 4. One day Melanie walked into Spencer's room to find him hitting himself on the head with a brick. He said he was trying to get his sadness and pain out. Overcome, Melanie hugged him, held him close and Spencer said in a small voice, "Mom, when Travis got cancer, it felt like somebody tore my body in half".

To Melanie, it was a wake-up call. Children with cancer get a lot of attention, but the pain and suffering of siblings are too often ignored. Melanie formed the organization SuperSibs! "to ensure that siblings of children with cancer are honored, supported and recognized... so they may face the future with strength, courage and hope". Melanie invites you to visit the organization's website at www.supersibs.org and to click on FOR YOU (for parents, teachers and medical/psychosocial support professionals) and the Sib Spot links (especially for siblings). We must always remember that when a child is diagnosed with cancer, siblings need support and healing, too.

Best wishes.

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