



Reaching Out to them
... Together
E-Newsletter

PALLIUM INDIA
CARE BEYOND CURE

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Dear Friends:

Rima died on 8 October 2008. She died in pain.

For those who missed it in our last newsletter, this sad news comes from Colombia. An ad had been placed in a newspaper in Colombia by Amine, the mother of Rima, a young person with cancer. She was addressing the Secretary of Health and she was pleading for morphine for Rima's pain. Rima did not get it.

Liliana De Lima from the International Association for Pain and Chemical Dependency writes to say that Amine "is willing to continue fighting so that this does not happen to other patients".

All strength to your hands, Amine. We cannot even imagine how agonizing your suffering must have been. We admire your determination.

Musical event on World Palliative Care Day

Music director M Jayachandran did it again! On 11 October 2008, World Palliative Care Day at the University Senate Hall in Trivandrum, he got together an amazing team performing a breath-taking musical event. His Worshipful Mayor of Trivandrum city, Sri Jayan Babu, our beloved "Sugathakumari teacher", film director and lyricist Srikumaran Thampi and actress Menaka joined the team in lighting a lamp to mark the opening of the event. Jazzy Gift, Vijay Yesudas, Vineeth Srinivasan, Chitra Iyer, Karthik, Sudeep, Sayonara, Roopa and Amritha Suresh were among the performers. We thank Mr Vivekanandan Nair and Mr Sumesh Lal and the whole team from ACV who telecast the program live!

The star of the day was Mr Ganesan, one of our patients, who took the trouble to come in his wheelchair and formally released the Malayalam monthly publication "Sahayatra" in its new form by handing over a copy to the Mayor. The Principal Secretary for Health, Dr Vishwas Mehta handed over a gold medal sponsored by Bruce Davis Trust, to Dr Unni S Pillai who had won in a competitive examination on palliative care held at Kochi. Palliative care activists Mr R S Srikumar of Sukrutham Palliative Care Society, Mr Francis Ernest who founded the palliative care program at Murukkumpuzha, Nurse Sheeba and volunteer Vasantha were honoured at the function.

IAHPC declaration: Palliative care and pain relief as human rights:

Many thanks to those who have signed the declaration proposed by the International Association for Hospice and Palliative Care. To those who have not been able to do it yet, here is a reminder. Please take a minute to sign the declaration online. 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>

An important reminder to all "Recognised Medical Institutions" in India.

Don't forget to submit your requirement for oral morphine for next year to the Drugs Controller in the appropriate form. If you need help, please contact us at pallium.india@gmail.com.

IAPC conference at New Delhi - 13-15 February 2009.

Another reminder: The next annual International Conference of the Indian Association of Palliative Care is going to be held at All India Institute of Medical Sciences, New Delhi from 13-15 February 2009. Please contact Dr. Sushma Bhatnagar, Organizing Secretary, IAPCON-2009 [R.NO. 242](mailto:R.NO.242@aiimspatna.com), Institute Rotary Cancer Hospital, All India Institute of Medical Sciences, New Delhi, Phone- 09811326453, 09811518929, Email- iapcon2009@gmail.com and shumob@yahoo.com

A vision for total care:

"Fortunately, with advances in technology and medical understanding, we can often treat cancer effectively", says Dr Harvey Fineberg, President of the Institute of Medicine, USA. "However, we tend to be less successful in caring for the psychological and social needs of cancer patients. Often, cancer patients need help in learning information and skills

to manage their illness. They and their loved ones also need help in facing emotional problems; finding transportation and other resources; and dealing with disruptions in work, school, and family life. These unmet needs can cause additional suffering and can hamper the patient's full recovery. By treating the disease instead of the whole person, our healthcare system fails to deliver effective and high-quality care."

The Institute of Medicine's report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, suggests a standard of care that incorporates psychosocial services into routine biomedical care.

This standard of care would include processes to:

- Identify psychosocial health needs;
- Connect patients and families to needed services;
- Support them in managing the illness;
- Coordinate the psychosocial and biomedical healthcare; and
- Follow-up on care delivery to evaluate the effectiveness of the services.

This vision for total care applies not only to cancer patients, but to everyone with an illness. By redefining care to include the whole patient, we can help make high-quality care a reality."

Why are we reproducing Dr Fineberg's comments here? We do not think there is anything much new in them. These form part of routine palliative care practice, but the point is, these are not messages to be received only by isolated hospices or by palliative care units in obscure corners of hospitals, but need to be conveyed loud and clear to the medical community at large. When will the day come?

Another step towards total care: a workshop at Vellore:

If the medical community is to recognize that management of any illness should be person-oriented and should include total care, it is essential that the necessary principles must go into medical curriculum per se. A workshop organized by the Department of Palliative Care at Christian Medical College, Vellore was another step in this direction. It was organized on 28 September 2008 in connection with the jubilee celebrations of Indian Medical Council and was attended by the vice chancellor of MGR Medical University, Dr Mir Mustafa Hussain and Dr Juliet Draper from UK. The workshop created a core curriculum on communication skills for incorporation into MBBS course.

Congratulations, Dr Reena George and team!

Marie Nyswander award:

This year's Marie Nyswander award was presented to Dr M R Rajagopal during the Annual Conference of the International Association for Pain and Chemical Dependency at Philadelphia on 31 October 2008 for his services to the field of pain management. This award is named after Dr Marie Nyswander who in the 1960s, with Vincent Dole, established methadone maintenance regimen for addiction and who changed the way the scientific world perceived addiction.

Dr Rosalie Shaw retires, and publishes her memoirs:

Dr Rosalie Shaw who has been the Executive Director of Asia Pacific Hospice Network (APHN) since its inception, retires soon. She moves from her current base in Singapore back to Australia. She had traveled far and wide in the Asia Pacific region educating doctors, nurses and other professionals. On behalf of all of us in the region, Rosalie, thank you very much for all that you did for our people.

Her book on her experiences with palliative care practice and education in the region have just been published on World Palliative Care Day. Look out for "Soft Sift in an Hourglass".

The Last lecture by Randy Pausch:

Dr V Nirmala from the Pallium India team says, talking about books, here is another one that you should not miss, "The Last Lecture" by Randy Pausch, a New York Times bestseller published by Hyperion in New York. Randy Pausch was a professor of Computer Science at Carnegie Mellon. Sadly, he died of pancreatic cancer on 25 July 2008. Months before his death, he gave his "last lecture" which made him an international celebrity. You can watch the lecture in youtube; the hour will be well-spent, we promise. Here is the link; don't miss it. http://www.youtube.com/watch?v=ji5_MqicxSo

Thank you for the feedback:

In our last issue, we had asked you for feedback about this e-news. Thank you very much for your responses, some of which we reproduce here.

This e letter is really informative; especially the U.P state statistics was really heart touching. Of course in developing countries like India still we have to speak much about Morphine availability. Really good coverage.

Dr.Lingegowda, Dept of Palliative care, Kidwai Memorial Institute of Oncology, Bangalore.

Thank you immensely for providing us with your Newsletter. The articles contain important messages drawing the pictures of SUFFERING PATIENTS asking for help, international SOLIDARITY but also sharing the diversity of palliative care problems in different cultures.
Jacek Luczak, ECEPT President, Poznan, Poland.

Pls keep on sending this newsletter; it is very nice to know.

Avnish panday

The heartbreaking stories of rampant uncontrolled pain from across India and the world are regularly featured in your newsletter. Along with this is the evident suffering of those who witness it and try to do something about it against all manner of formidable obstacles. As long as there are such people who care deeply, and have the knowledge and will to make a difference, there is hope.

Thank you for allowing us to be part of your community.

Dr Paul Mathew, Houston, Texas.

Dear Editor, like David Clark I enjoy reading your choice of material. While it is relevant globally it also allows me to hear of problems and successes in India. Keep it up.

Dr Michael Minton, Oxford, UK.

The newsletters are truly heartwarming, informative and inspiring. Please continue to keep me on your mailing list

Dr Reena Mary George, Vellore, India.

Thanks for sending this wonderful Newsletter and I agree with David Clark in that they are fascinating. My only suggestion is to include the names of the editor(s) and those contributing to each article. Or if its done by a group of people, then their names could be placed at the end or beginning of the Newsletter.

Thanks for giving us the opportunity to contribute and for asking our opinion. Best regards,
Liliana De Lima, MHA, IAHPC Executive Director

With best wishes,

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