

Reaching Out to them  
*... Together*  
E-Newsletter

**PALLIUM INDIA**  
CARE BEYOND CURE

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April 7, 2009

Dear friends

Greetings to you on World Health Day!

Sixty one years back – on 7 April 1948 - the World Health Organization declared that “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”

This definition has not been popular with all doctors. Some have argued (for example, Saracci R, BMJ, 10 May 1997, 314:1409) that it is too ambitious and that kind of health is unattainable. Saracci argues that Health should be redefined thus: "Health is a condition of well being free of disease or infirmity and a basic and universal human right." As if freedom from disease and infirmity is always attainable!

What would we like from the health care system if we were the patients? Would we like a totally disease-focused approach, or would we like the health care delivery system to care for our mental and social well-being too? Would we just have them look at us through precise imaging systems or would we like them also to sit down beside us for a moment and ask us how we feel?

Palliative care has truly given a practical applicability to the WHO definition of Health. Let us hope for the day when the Health care systems of the world take a good look at what palliative care does, and start thinking how much of it can be applied to routine health care.

## **Responses to Report from Human Rights Watch:**

Well, even if a state of perfect health is universally unattainable, how about (at the very least) access to pain relief and palliative care? We are very happy to see the excellent responses from around the globe to the report from Human Rights Watch. Thank you once again, Diederik Lohman and colleagues.

Those who have not seen it yet, please visit <http://hrw.org/en/node/81080/>

## **Liliana's report in IAHPC newsletter:**

Liliana De Lima wrote about her Indian visit and her impressions in IAHPC newsletter ([http://www.hospicecare.com/news/09/04/reflections\\_india.html](http://www.hospicecare.com/news/09/04/reflections_india.html)). It drew several responses. Some of them have been complimentary; some almost angry.

Essentially, one message that we need to take from Liliana's report is very similar to what Dr Jan Stjernsward said about eight years back. Some of us were preening about the "Indian success story" and Jan, rather bluntly, said that "all considered, the progress in India has been rather disappointing".

Eight years down the line, things have not improved that much! This should be a time for introspection. What have we been doing wrong? What can we do to reach those millions? Liliana argues for international funding directed at reaching those areas in the country that have no palliative care now. It is true that the country should not depend on international funding alone and should look for effective use of available local resources. But it is also true that we need to draw on all possible resources – international or national. And international support does help. We had started in Calicut in 1993 with a capital of Rs.1500 (something like \$ 30). An unconditional grant of Rs. 100,000 from Ms Gilly Burn helped us to spread our wings and fly! Timely help from American Cancer Society to a Pallium India-INCTR project helped MNJ Cancer Institute to develop a training center in Hyderabad. A Pallium India project undertaken jointly with Pain & Policy Studies Group (PPSG) and National Cancer Institute (NCI) helped create palliative care centers in Manipur and Mizoram – two states which till then had no palliative care at all. Now that the support is over, local efforts keep them going. And more recently, another Pallium India-PPSG-USCPRC (United States Cancer Pain Relief Committee) project is working on UP, Jharkand and Bihar to get palliative care programs going in cancer centers.

And Pallium India is sitting on a list of 28 cancer centers in the country that want to start palliative care services and are looking for some support! We estimate that about \$ 33,000 over a two year period would help a good program to take root and enable sustainability in a couple of years! If you know of someone who will help, please write to us.

### **Refresher course in Palliative Care; Trivandrum, 30-31 May 2009:**

Pallium India announces a Refresher Course in Palliative Care at Trivandrum on 30, 31 May 2009. Day 1 will be devoted mostly to symptom control, and we expect, doctors will be more interested in this than others. Day 2 will be on psycho-socio-spiritual issues and should be of interest to anyone connected with palliative care. National and international faculty members will conduct interactive sessions mostly based on true stories of patients. Participants can register either for the whole event or for the second day only.

Registration fee: Rs. 500 both days together

Rs. 250 for day 2 only

Low cost accommodation can be provided for those who require it. If you are interested, please write to [pallium.india@gmail.com](mailto:pallium.india@gmail.com)

### **Thank you Mr Tony Devassy!**

Mr Tony Devassy who heads "Care and Share" in USA visited us recently. Care and Share has been supporting Pallium India and many charitable activities in the country for a long time. Pallium India came across 'Care and Share' through our long time friend and well wisher Dr Philomina Thuruthumaly - a kind and compassionate doctor working in USA. Since then Care and Share supported us in many ways. The vehicle that we now use for home visits was donated by Care and Share in 2008.

Mr Tony Devassy found time to travel from Kochi to Trivandrum during his brief holiday. He handed over a cheque to cover the loan scholarship of a medical student for whom continuation of medical studies became a huge challenge because of sudden illness in the family. Thank you, Care and Share!

## **Palliative care fellowship at Vellore.**

Admission to the one year residential fellowship at Christian Medical College, Vellore is open. Selected candidates will be paid a monthly stipend and provided accommodation. Those interested, please write [toedupall@gmail.com](mailto:toedupall@gmail.com). Phone: 0416 2283 159; 09944 266 134.

## **Manitoba Palliative Care Research Unit: Post-Doctoral Fellowship: 2009-2011**

Ms. Mary Callaway informs us about a two-year post-doctoral fellowship in palliative care research from The Manitoba Palliative Care Research Unit (MPCRU). Preferred candidates would have completed a PhD in the past two years, have an excellent academic record, some record of publication and have a strong research vision. Those interested, please visit <http://www.cihr-irsc.gc.ca/>.

## **Trigeminal neuralgia guidelines available**

The American Academy of Neurology and the European Federation of Neurological Societies have issued evidence-based guidelines related to the diagnostic evaluation and treatment of trigeminal neuralgia. The guidelines recommend controlling pain with carbamazepine. Oxcarbazepine should be considered, and baclofen, lamotrigine, and pimozone may be considered. However, topical ophthalmic anesthesia should not be used. If the pain is refractory to medical therapy, physicians may consider early surgical intervention and percutaneous procedures on the Gasserian ganglion. Gamma knife and microvascular decompression are also options. <http://www.guidelines.gov/summary/summary.aspx...>

## **How reliable is our “Evidence based medicine”?**

These are days of evidence based medicine. My choice of drugs for the patient’s benefit should not be based on my “gut feeling” which could well be misleading. My choice should be based on the results of scientific studies. Perfect, is it not?

But how reliable is available evidence? 90% of all scientific studies on drugs are funded by the pharmaceutical industry. Can we rely on all of them to come out with the whole truth? And to publish results that are disadvantageous them?

Sen. Charles Grassley from USA points out that the pharmaceutical company Wyeth used unidentified medical writers to produce medical journal articles favorable to Prempro, at least one of which was published after the drug was found to increase breast cancer risk!

What do you feel about the industry using unidentified medical writers for medical journal articles? If you oppose it, perhaps you would want to vote against the practice? Please go to <http://www.medscape.com/px/instantpollservlet/vote?PollAnswer=1&PollID=3006&URLForRequest=%2Fpx%2Finstantpollservlet%2Fresult%3FPollID%3D3006%26BackURL%3D%2Fpx%2Finstantpollservlet%2Fresult%3FPollID%3D3006&vote=Vote>

### **Denial of treatment to HIV positive person:**

Human Rights Law Network reports: The Supreme Court of India issued notice on 18 September 2008 in an application filed on behalf of an HIV positive person (known as ABC) from Bihar. ABC is in need of second line antiretroviral treatment, but was refused the necessary treatment at a Hospital in Mumbai, on the ground that he was not a resident of Maharashtra.

The application was filed as part of the ongoing public interest litigation brought by the Voluntary Health Association of Punjab and currently running in the Supreme Court.

ABC was advised by his doctors in Bihar in December 2007 that he needed second line treatment, having developed a resistance to first line treatment. No public hospital in Bihar stocks second line drugs or makes them freely available. ABC therefore traveled to this hospital in Mumbai, where he knew there was a second line ARV treatment program. The doctors at the Mumbai Hospital refused, however, to provide ABC with the required drugs, citing the fact that he was not a resident of Maharashtra.

The application filed in the Supreme Court on ABC's behalf cites Article 21 of the Indian Constitution, which protects every person's right to life, as placing an obligation on the Government to ensure the availability of ARV drugs free of charge to people who require them, regardless of whether they are first or second line drugs and regardless of where the person in need lives.

Shocked at the callousness of the Hospital? We are not! We know that even today, many hospitals in the country turn away HIV positive people on flimsy grounds!

## **Thank you Sue. You live in our hearts!**

Mrs Sue Treadwell died of a stroke on 29 September 2008, at the age of 54. She leaves behind Simon Treadwell, her husband, two sons and a daughter.

Born in Yorkshire, UK, in 1954, Sue's passion for helping the less privileged manifested when at the age of 14 she walked and finished a sponsored 25 mile walk for sick and handicapped children. In 2006 and 2008 Sue and a friend took part in sponsored walks for Macmillan Cancer Care - firstly in Peru to Macchu Pucchu and then in the Sahara. They raised approximately £20,000. For the past 18 years she worked as a counselor at a Doctors Practice in Guildford. Her understanding and guidance helped many patients through depression, bereavement and family troubles.

Sue's parents have created a fund which now supports palliative care and treatment support through Pallium India. Thank you, Sue. You live on in many peoples' hearts.

## **Protect children from second hand smoke:**

To protect children against cancers caused by second-hand smoke, we must give them an environment that is 100% smoke-free. A symbol was designed to indicate and promote safe, smoke-free environments and increase awareness about the opportunity to protect our children from cancer. It is the result of an international competition launched by the International Union Against Cancer (UICC) as part of its World Cancer Campaign.

The symbol should be used at home, in private vehicles, play grounds and all other places where children live, learn or play. It can be printed on stickers, posters, and placards. It can also be displayed on websites to advertise places or institutions where children are protected from second-hand smoke. If you are interested in helping to disseminate this symbol, please contact the UICC campaign team ([wcc@uicc.org](mailto:wcc@uicc.org)).

## **Annual conference of IAPC at Trichy.**

Before we sign off, let us remind you about the next annual international conference of Indian Association of Palliative Care at Trichy, Tamilnadu, India. There will be pre-conference workshops on 11 February 2010 followed by the three day conference from 12<sup>th</sup> to 14<sup>th</sup> February

2010. Dr T. Mohan Sundaram is the organizing secretary. You could do the Early bird registrations now and save some money! Please contact [drmoht.trichy@hotmail.com](mailto:drmoht.trichy@hotmail.com).

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