

EAPC-East Newsletter NR 2 – April 2002

Dear Friends!

This, our second newsletter is sent to all affiliated to the EAPCeast web site, EAPC board and also to persons active and interested in palliative care in Eastern Europe to whom we have an e-mail address. In the future we will distribute the Newsletter to those registered at our web site - so hurry up and register - www.eapceast.org

Practicalities -goods

Has been. First some really good and practical news since last time. The Swedish Company Clean Disc, clears computers from information, sent 5 well functioning and clean computers to the palliative centre in Riga, Latvia for Dr Vilnis Sosars at his disposal.

Will be: Stockholms Sjukhem has changed linen and beds etc. We will donate a number of beds. The beds are vertically adjustable and regulated with manpower, or rather foot-power. The linen and washing routines have changed at Stockholms Sjukhem and linen with Stockholms Sjukhem's logo will no longer be used so we are offering sheets, pillowcases, towels etc.

If you are interested to get adjustable beds, sheets, china, towels etc please go to web site www.eapceast.org under forum for more information and to possibly sign up. When we know the amount of units interested we will work to arrange transportation.

Call for Standards of Palliative Care

We are collecting Palliative Care Standards already worked out by different units, regions or countries. As we mentioned in the last Newsletter, on the EU-project we have applied for, it consists of different parts. One part is to get consensus on minimum palliative care standards. Before we can work on a consensus we would like to know more about the standards already written. We know there is lots of efforts put in producing standards and we are very interested in all initiatives, already ready or as drafts. We have already:

Irish and Hungarian standards and standards for Nurses in Canada as well as UK standards for nurses to prescribe for palliative care.

We are planning to compile and make use of the work already done. Please send us the standards you have, already fully worked out or just in draft. If they are not in English please help us out by translating the headlines.

By e-mail: Sylvia.Sauter@stockholmssjukhem.se

By postal mail you can send it to:

Sylvia Sauter

Palliative Care in Eastern Europe – an EAPC project

Stockholms Sjukhem

Mariebergsgatan 22

112 35 Stockholm

Sweden

Palliative care organisations

During the last few years the interest for palliative care in Eastern Europe has grown. People working in palliative care join in organisations to be able to share with one another. This is clear from the number of national and regional organisations that have started.

We would very much like to get in contact with the organisations and know more e.g. the aim of the organisation, contact persons etc. I have sent a list with the information on the palliative care organisations in Eastern Europe and I have asked some people in each country to provide me additional information.

If you have information of interest, please let me know. You find the current list of organisations on our web site www.eapceast.org under download. Please feel free to send me the information you think might be useful.

National OSI foundations supporting palliative care

The following OSI foundations have committed themselves to support palliative care in their respective country: Azerbaijan, Bulgaria, Czech Republic, Georgia, Hungary, Lithuania, Moldova, Russia and Slovakia. This means that you can try to apply for funding for projects, travelling or courses.

Those living in other countries than those mentioned above should try to get funding from their local OSI foundation anyway, Mary Callaway from OSI - New York suggests. The OSI foundations should be informed of the needs for development and funding of palliative care.

Samples of palliative care events and activities in the Eastern European Countries

5th National Hospice-Palliative Congress of the Hungarian Hospice-Palliative

Association. The national congress will be held May 17-18, 2002 in Kecskemét. The main topics are: palliative medicine, management and bereavement. The second edition of the National guidelines will be presented.

For further information please contact:

Prof Katalin Hegedus , e-mail: hegkati@net.sote.hu

New Hospice in Budapest

The Budapest Hospice House, due to be opened by Hungarian Hospice Foundation later this year, represents a further stage in the development and improvement of services for the entire hospice movement in Hungary. The office co-ordinating home care started operating this year in the building leased from local council under favourable terms and conditions. A centre providing therapy support and a hospice-training centre will also start operating shortly. The Budapest Hospice House also plans to have an inpatient unit with up to 10-15 beds, with these facilities expected to be ready within 1-2 years. The first wing of Budapest Hospice House will be officially opened 24 May, 2002.

For further information please contact

Melinda Szöllősi, Hungarian Hospice Foundation

e-mail: mhospicea@axelero.hu, web-site: www.hospicehaz.hu

Romania

SRPT has started a **project** in cooperation with the University of Maastricht. The name of the project is "Palliative Care in Romania" (PACARO).

This project started February 2002 and will be ended 30 month later.

This MATRA project aims to demonstrate the possibilities for palliative care in Romania, to develop adequate and generally accepted models for care to terminal patients and to guarantee quality in palliative care.

The overall objectives are described in 8 steps:

- Building up regional palliative teams;

- Training nurses, GPs and medical specialists (oncologist) to work in the field of palliative care (including quality assurance);
- Developing protocols for palliative care;
- Demonstrating the feasibility of regional palliative care teams;
- Evaluating the outcomes of the regional teams;
- Developing a network for palliative care together with SRPT;
- Writing a handbook for developing palliative care in Romania;
- Implementing the protocols and organisational models for palliative care in Romania.

In Slatina, September 2002, there will be a **National Conference** with invited international experts.

For further information please contact:

Dr. Gabriela RAHNEA-NITA , SRPT Secretary

e-mail: andreis@pcnet.ro

Slovenia

In Logarska dolina, Slovenia Palliative Care Development Institute is organizing workshops on "Breaking bad news" for medical doctors, April 18-19, May 30 - June1, and September 17-18, 2002.

In Ljubljana, there will be a meeting of teams in primary care service with part of the topics covering palliative care May 18–19.

Workshops for teachers titled "Coping with loss in classroom" will start on October 17-19, and November 7-9.

Together with the Institute of Oncology a seminar on "Burnout in working with dying" with invited international experts will be arranged, November 22–23.

In Maribor, there will be a seminar on "Pain management" with palliative care topics included, June 6–8.

Open forum titled "When your child becomes seriously ill" will take place in October 2002.

For further information please contact:

Branka Cerv, RN, BSc, professional associate

e-mail: branka.cerv@mail.ljudmila.org

Report on the Meeting in Budapest, on Availability of Opioids

WHO EURO Sponsors Workshop on Assuring Availability of Opioids Analgesics for Palliative Care in Eastern Europe

Foley K, Callaway M, Palliative Care Initiative, Open Society Institute, NY, NY
de Jonchere K, World Health Organization Regional Office for Europe , Copenhagen, Denmark, Joranson D, Ryan K, Policy Studies Group, University of Wisconsin, Madison, WI

More than 40 experts from Bulgaria, Croatia, Hungary, Lithuania, Poland, and Romania convened at the Central European University, February 25-27, 2002 in Budapest, Hungary, to evaluate national policy and develop action plans for improving opioid availability for palliative care in their countries. Representatives from the ministry of health, narcotics control, national cancer control program, pain and palliative care clinicians, and NGO's working in the field participated. The workshop was organized jointly by the WHO Regional Office for Europe in Copenhagen, with support from the World Health Organization,

Essential Drugs and Medicines Policy Division in Geneva, the WHO Collaborating Centre for Policy and Communications in Cancer Care, in Madison, Wisconsin and the Open Society Institute's Palliative Care Initiative in New York.

The meeting was the first of its kind in the region to bring national and international experts from various disciplines to the table to learn from one another and to discuss their individual roles in achieving adequate pain management for patients suffering from life threatening disease. The workshop provided the participants with the knowledge base necessary to evaluate their national opioid control policies, and the necessary assistance to determine what, if any, changes need to be made in the laws, regulations or drug distribution in their countries to improve the medical use and availability of opioid analgesics. The recently published World Health Organization Guidelines "Achieving Balance in National Opioids Control Policy"¹ was used as the basis for policy evaluation to identify potential barriers to opioid availability in the national opioids control policies of the participating countries.

Dr. Cecilia Sepulveda, Coordinator of the WHO Cancer Unit in Geneva, discussed the WHO cancer pain relief and palliative care program. Dr. Kathleen M. Foley, pain and palliative care expert from Memorial Sloan-Kettering Cancer Centre in New York, described the problem of pain in AIDS and the assessment, management, and under treatment of pain. David Joranson, MSSW, Director of the WHO Collaborating Centre in Madison, Wisconsin detailed the barriers to opioid availability and opioid consumption in Eastern Europe, and Tokuo Yoshida, from WHO Essential Drugs in Geneva described the role of U.N. Agencies in ensuring the availability of opioid analgesics.

Individuals from each participating country reported on the prevalence of cancer and pain in their country, the nature and extent of opioid availability or unavailability, opioid consumption trends and prescription requirements, and existing pain and palliative care services. Opioid consumption varies widely among the countries represented, as does access to adequate pain and palliative care services. In addition, the most cost-effective drugs are not always available or being used for treating pain. Market conditions, distribution systems and regulations are important factors that affect local availability. There may also be important differences within countries with rural areas.

Participants recognized the need to balance the regulatory requirements for the control of opioids with the need for making opioids accessible for appropriate pain relief. Governments should ensure the accessibility of opioids for their population while complying with all international regulatory obligations. Representatives indicated that prescription and dispensing regulations should be reviewed, as they may be seen as too restrictive, and an impediment for making opioids accessible. Public and professional education is needed that will stress the need for appropriate pain treatment

The proceedings of the workshop will be published by the WHO Collaborating Centre for Policy and Communications in Cancer Care in Madison, Wisconsin and will be available on their website <http://www.medsch.wisc.edu/painpolicy>.

World Health Organization. *Achieving Balance in National Opioids Control Policy: Guidelines for Assessment*. Geneva, Switzerland: World Health Organization; 2000. (Available at <http://www.who.int/medicines/library/qsm/who-edm-qsm-2000-4/who-edm-qsm-2000-4.htm>).

**Report on the Conference on palliative care in Zagreb, Croatia, 21-23 March 2002:
key issues in palliative care and its solutions in family medicine.**

This three-day conference was the fourth conference of the Croatian Society for Hospice and Palliative Care, chaired by the pioneering and enthusiastic president of the association, professor Anica Jusic. The conference was held under the auspices of the Ministry of Health of the Republic of Croatia and the Minister of Health of Croatia, Dr Andro Vkahusic, has encouraged the formation of a Palliative Care Committee in Croatia. This shall be seen as an important step towards integration of palliative care in the Croatian health care system. The Group met for the first time during the conference and there were representatives from the Ministry, the Medical Faculty of the University of Zagreb, Family Medicine, Oncology and the Croatian Society for Hospice/Palliative Care, including Professor Anica Jusic.

There were additional members from other countries, Professor David Clark from the University of Sheffield, UK, Mary Callaway from the Palliative Care Initiative, OSI, New York, USA, Professor Katalin Hegedus from Semmelweis University of Medicine, Budapest, Hungary, Dr David Oliver from the Kent Institute of Medicine and Health Sciences at the University of Kent at Canterbury and Dr Carl Fürst from Stockholm and the European Association of Palliative Care,

During the conference palliative care was exposed from different perspectives, national and international (Croatian, Hungarian, European and American), historical, present and future development. These topics were discussed from the point of view of palliative care development in Croatia. Presentations were translated to English or Croatian and made the conference very interesting also for the invited speakers from Hungary, England, Sweden, Scotland and the US. Participation of volunteers in palliative care were also discussed as well as social acceptance of death and palliative care put in an historical concept. Also quality of dying, futile treatments, and when to stop treatment in end of life situations were covered by lectures and round table discussions. A generous social program and a good opportunity to get acquainted with the beautiful Croatian capital, Zagreb, created fine opportunities for networking and getting to know new colleagues.

Dr Carl Johan Fürst, EAPC Coordination Centre for Eastern Europe

If you know of someone who would like to get the Newsletter, please let us know, if you prefer not to be included in the mailing list please let us know.

Looking forward to hearing from you!

Sylvia Sauter

Carl Johan Fürst