EAPC-East Newsletter NR 17– December 2003

This last EAPC-East Newsletter for 2003 is longer than usual because we wanted to give you direct access to all the plans and participants from the meeting in Budapest October 2003 on changing palliative care policies. But we wanted to squeeze in some other information as well. Hope your mailboxes make it!

Council of Europe Recommendations for palliative care - for all of us

The final recommendations by the 45 countries were adopted by the Committee of Ministers with favorable comments on November 12, 2003. The official disclosure is not yet published but the semi-official file can be down loaded from the web site www.eapceast.org
The recommendations will be sent to each country, but only sample copies. The member state can buy more copies from the Council of Europe during the first 6 months – they are supposed to distribute them.

We – EAPC are now discussing how to do a joint activity in Europe to spread the knowledge about palliative care and about the recommendations. The plans include you all! If you have ideas for how to disseminate into the communities, please let us know!

1st Conference of Bulgarian Association for Palliative Care, Sofia, Bulgaria 5 – 7 February 2004

The accents of the conference are:

- gathering and exchange of experience,
- promotion of standards in palliative care
- initiation of changes in the healthcare policy for palliative care to be accessible
- educational aspect of palliative care in colleges and universities will be discussed as well.

The foreign guests who will be present will share their experience in terms of organization, financing and methods of work. There will be simultaneous Bulgarian-English and English-Bulgarian translation

It is the first event of its kind in Bulgaria and we will be glad to welcome as many participants as possible from whole Bulgaria maximum being 60 participants.

The event is financed by Open Society Foundation and there is no fee to attend. For further information and application please contact Ms Iglika Gardeva, palliativecare@abv.bg

ABC of Palliative Medicine from BMJ

Difficult pain problems by, J Sykes, R Johnsson and GW Hanks is the third article from BMJ's clinical articles on palliative care that you can down load from the EAPC-east web site. www.eapceast.org

Action plans for palliative care in 12 different countries

Here are the written plans and the participants from the attending countries in the Budapest meeting on changing policy on palliative care, October 03

Hopefully this information will inspire you to ask for progress on the plans to the appropriate persons in your respective country. Good luck!

Bulgaria - Goals and Action Plan

To develop palliative care standards

• Create a workgroup to prepare national standards with financial support from Dept of Health and Informational resource—one year deadline

Change Opioid Law

• Create a work group including MoH, National Insurance Institute, Health Group of Parlament with support from colleagues from EAPC—one year deadline

Include home palliative care in National Health Insurance

• Create working group with professional physicians organization that will present suggested package who should buy financing from health system—*three year deadline*

Alexandrov Stoyan, Director of Directorate Diagnostic and Curative activities, Ministry of Health, Sofia, deserration-deserration-deserration-deserration-deserration-deserration-deserration-deserration-deserration-deserration-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-deservation-dese

Kalinka Balabanova, Teacher Medical College, Plovdiv, <u>medcolpv@plovdiv.techno-link.com</u> *Dimitar Dimitrov*, Chairman Bulgarian Ass for Palliative Care, Plovdiv, <u>dimitrovmd@abv.bg</u> *Sashka Ruskova*, National Health Insurance Fund, Chief of Dept of Hospital Care, Sofia, <u>sruskova@nhif.bg</u>

Czech Republic

- Improve the cultural-social background and the education of the society
- Cultivation of a dying process in long-term care facilities
- Effective client-focused financing

Improve the cultural-social background and the education of the society

- Translation of the WHO and COE publications on PC and present them on the national level for politicians and decision makers (Launched with OSI and other international PC celebrities)
- Try to improve the media made picture of the health reform as bringing not only restrictions of resources (financial) but as bringing an effective improvement of quality of care (using PC as a model of improving type of care of progressively ill people)
- Coordination and unifying the experiences and points of views of NGOs and all other subjects aiming at improving the care of progressively ill people
- Using well-known and/or important persons of public life to initiate a public discussion about all the questions related to death and dying in comparison with a current poor situation in this field

Cultivation of the dying process in long-term care facilities

- 1. Re-structuralisation of types of care for those who are cared in long-term care facilities
- 2. Identifying groups of patients according to their unmet needs
 - a) palliative terminal care pts. b) rehabilitable (convalescent) pts.
 - c) chronical basic nursing care pts. d) residential pts. (respite care)
- 3. Using minimal data sets and Comprehensive Geriatric Assessment
- 4. Interdisciplinary consensus within all the responsible participating subjects Geriatric and

Palliative Care Societies

- 5. Supporting home-based care and home-based palliative care as a comprehensive and complex care provided by multiprofessional teams to reduce the number of hospitalisations
- 6. Supporting hospital-based palliative care teams and/or clinics

Effective client-focused financing

Precise financing of PC according to defined needs of patient groups (categories)

- Prognosis (estimated life expectancy) and counselling needs
- Symptom severity pain, passage + nutrition, dyspnoea, fear/anxiety/depression
- Severity of skilled nursing
- Severity of basic nursing (ADL)
- Family support needs (bereavement)

Zdenek Bystricky, Physician District Hospital, Blansko <u>zdenek.bystricky@worldonline.cz</u> ZdenekKalvach, Senior lecturer of geriatrics and internal medicine, Charles University, Prague, kalvach@lfl.cuni.cz

Antonin Pecenka, Head of Departmen of Health Care, General Health Insurance Company, antonin.pecenka@op99.vzp.cz

Martina Spinkova, Director Home Palliative Care Service-Cesta Domu, Prague, cestadomu@cestasdomu.cz,

Ludmila Vostrakova, Director, Social Health Care Department, Ministry of Health, ludmila.vostrakova@mzcr.cz

Hungary Goals and Action Plan

To include the PC into the existing health care system Minimum standards

- •Means to define clearly the meaning of PC
- •Providers of PC (numbers, education)
- •Minimum level of care in different organisational forms It is the basis of the legal existence of PC in the health care system Pilot project to integrate PC into public health
- •Elaboration of a two years model program for helping the integration
- •Ask for applications

Set up the financial backgrund (NHS) of PC

Goal: financing of 70% of PC costs

Action Plan

- •31 October 2003 elaboration of minimum standards
- •31 March 2004 quality insurance to modification of regulation
- •30 April 2004 ask for application
- •1 July Launch of model program

Ferenc Alfoldy, Senior Councellor of medical and nursing department of Ministry of Health, Social and Family affairs, alfoldy.ferenc@eszcsm.hu

Csaba Dozsa, Deputy Director General for Health policy and Health Care, National Health Insurance Fund, csdozsa@oep.hu

Ferenc Falus, President National Health Council, ffalus@axelero.hu

Arpad Gogl, President Monitoring Subcommittee, Health Care Committee Hungarian Parlament, arpad.gogl@parlament.hu

Katalin Hegedus, member of board of directors of EAPC, professor of bioethics,

Semmelweiss Medical University, Budapest, hegkati@net.sote.hu

Eva Kereszty, Leader of medical and nursing department of Ministry of Health, kereszty.eva@eszcsm.hu

Agnes Ruzsa, President of Hungarian Hospice-Palliative Association, Chief of the oncological department, Zalaegerszeg, ruzsaagi@zelkanet.hu

Lithuania - Goal

To integrate Palliative Care (PC) in the National Health Care System using the existing situation and resources

TASKS

- •The preparation, confirmation of the legal basis
- •Analysis and reallocation of resources
- •Raising awareness and education

The preparation and confirmation of legislation basis

- •Evaluation of the existing legislation basis and suggestions for the changes, and confirmation
- •The preparation PC norms and standards and confirmation
- •The preparation of PC strategy and confirmation

Analysis and reallocation of resources

- •Evaluation of existing human, financial and institutional/technical and structural resources.
- •Preparation recommendations of the reallocation of the resources and presentation to the discussion for the Health Care Ministry.

Awareness and education

- •To prepare qualification standards for specialists in palliative care
- •Create PC certification system
- •Advance existing under-graduate and post-graduate programs in PC
- •Involve PC in Public health care prevention programs
- •Media: TV, radio and etc.

Nijole Bieliniene, Chief Specialist, Division of Health Care, Ministry of Health, nijole.bieliniene@sam.lt

Rita Kabasinskiene, Director Kaunas Nursing Hospital, kaunosl@takas.lt

Arvydas Seskevicius, President of Lithuania Palliative Care Association, Kaunas University of Medicine, Kaunas, <u>slaugaar@kmu.lt</u>

Alfreda Taminskas, Chief Expert, State Patient Fund, Ministry of Health, medeks@vlk.lt Raimonda Ulianskiene, County Physician, Panevezys County, sveikata@pava.lt

Republic of Moldova

Palliative Care Policy Development of Republic of Moldova

- Creating a National Commite of PC for development and implementation in Moldova
- Forming a workgroup and appreciate the need of financial support
- Analysis and focusing on cohort of patients who need PC
- Informing the population about the possibility of PC
- Revision of legislation in Republic of Moldova

Elena Boleac, Deputy-head of the Program, Licence and Accreditation Department, Ministry of Health, Chisinau, phone: 373 2 725892

Iurie Bulat, Principal Scientific Researcher, Institute of Oncology, President of the Scientific Society of Oncologists of Moldova, Chisinau <u>ibulat@mail.md</u>

Minodora Mazur, University professor State Medical university, N Testemitanu, Chisianau, mminodora2001@yahoo.com

Svetlana Popovici, Physician, Department for treatment of HIV/AIDS patients, Chisisnau, phone: 373 2 794103

Gheorghe Rusu, Director National Health Insurance Company, Chisinau, phone: 373 2 727676, 727367

Poland Goals and Action Plans

Goal 1

To raise awareness of hospice/palliative care

- -in national and local authorities
- -among health care professionals
- -in general public

steps to be taken

- ullet To restore the activities of the National Council for Hospice/Palliative Care as advisory body of the MoH 6 months
- •To promote and to extend PC education among professionals continuously
- •Public campaign through national and local media (using Hungarian experience) continuous/repeated

Goal 2

To cover the *blank patches* on the PC coverage map of Poland steps to be taken

- •Local needs assessment (including non-malignant diseases, AIDS)
- •Strategic planning (SWOT)
- •Recognise and adapt effective experiences of other countries
- •Establishing hospital and nursing homes PC supportive teams
- •Promotion of PC approach among primary care professionals
- •Lobbying health authorities at all levels for improvement in financing of palliative/hospice care
- •Financial compensation for primary caregivers
- •Reimbursement of essential drugs in PC

Goal 3

To introduce compulsory program of PC education to all medical universities

steps to be taken

•Lobbying National Council of University Education and rectors of medical schools focused on inclusion of palliative medicine/care in all curricula

Maciej Kluziak, Secretary, ECEPT-Eastern and Central Europe Palliative Care Task Force, Poznan, mkluziak@polbox.com

Katarzyna Kowalewska, President, Hospice of Kutno, NGO, hospicjumkutno@poczta.onet.pl *Agnieszka Lewicka*, Department of European Integration and International relations, Ministry of Health, agalewicka@tlen.pl

Anna Marzec-Boguslawska, Managing director, National AIDS Center, Warsaw, aids@aids.gov.pl, dyrekcja@aids.gov.pl

Romania - Goals and Action Plan

To transform the taskforce group into a commission of the Ministry of Health Report for the MoH that would contain the actual situation in Romania, the actual situation in the region, the recommendation of WHO and Council of Europe and also the countries where they have a commission in their MoH

- •Need letter from WHO, Responsible Eugenia Anca
- •Deadline November 30, 2003

To release the order of Minister of Health for Palliative Care that would acknowledge the structures able to provide pc

- •Need cost efficiency analysis use Catalonian model
- •More complex assessment of the needs
- •Develop complex documentation

To develop a seminar for the possible authorities involved in developing the pc structure in Romania

- •MoH to organize
- •Experts to be invited
- •Participants to include house of insurance, MoH, press, representatives of the cancer patients associations and other associations, medical reps, and NGOs—Spring 2004 Financing to be determined

Eugenia Anca, Councellor in the General Department of Medical assistance, Ministry of Health, ancae@ms.ro

Oana Donea, Oncologist, Palliative care trainer, St Luca Hospital, Bucharest Daniela Mosoiu, Director Study Centre for Palliative Care, Brasov, mosoiudaniela@xnet.ro

Slovakia - Goals and Action Plan

- 1. Enable home palliative care provision
- •Amend the existing legislation (Act on Health Care) that not only GPs and nurses can provide health care at home, but also physicians specialized in palliative care and other health professionals
- •Legalize visiting and activities of volunteers at home of palliative patient

2. Establish palliative care provision in existing health care institutions

- •Use the ongoing health care reform to change acute beds into palliative beds
- •To offer this possibility not only in health sector, but also in other sectors health care institutions (defense, interior, etc.)
- •Cooperation with social sector (social care institutions)
- 3. Elaborate obligatory national standards
- •Educate providers of palliative care, health care professionals and general public at international level
- •Unify the conditions for palliative care provision in all settings
- •Define minimal and optimal standards for different settings

Miriam Cejkova, Chair of Palium, NGO, Bratislava, <u>palium@palium.sk</u>
Monika Gojdova, Expert Advisor department of European Affairs, Ministry of Health, <u>gojdova@eudoramail.com</u>

Patricia Porubcanova, Ass professor of faculty of Health care and social work, Trnava University, phone: 421 907 695 074

Kristina Krizanova, Head of Palliative Care Department, National Cancer Institute, Bratislava, <u>Kristina.krizanova@nou.sk</u>,; krizan@milosrdni.sk

Slovenia - Goals and Action Plan

Recruiting and motivating health care professionals

- We are going to present needs of PC in Slovenia at Slovenian Physician Congress at workshops where a physician and a nurse and one family member of a terminally ill patient present their view of the problem. We will discuss these problems with family doctors. The same presentation could be done at Congress of Nurses.
- We will write an article about PC in review of Slovenian physician journal

Pilot study: implementation of pc into three hospitals and regional primary care organizations. We are going to start pilot studies in 2 University and 1 General Hospital after 1 year we are going to evaluate the results and it will be the keystone at the negotiation with health care providers and Ministry of Health Education

• We have already started the program for physicians and nurses but we would like to have support of more experienced

Epidemiologic situation

• We are going to set up a framework of PC providers on the basis of epidemiological studies

Jozica Jost, Head Nurse, University clinic of Respiratory and Allergic Diseases, Golnik, jozica.jost@klinika-golnik.sl

Urska Lunder, Director, Palliative Care development Institute, Ljubljana, urska.lunder@mail.ljudmila.org

Nadja Triller, Specialist in Internal Medicine and Pulmonology, University Clinic of Respiratory and Allergic Diseases, Golnik, nadja.triller@klinika-golnik.sl

Mongolia - Goals and Action Plan

Financing

- •Perform a country needs assessment of financial resources
 - What--
 - When
 - Who

Establish Home Care Service in Provinces and Districts

- Policy
 - Advocacy
 - Develop Minister's order on palliative care services
 - Establish pc team at provinces and districts
 - Drug prescription right and availability
 - Coordination and regulation of pc services
 - Review and make changes in related laws, ordinances, and legislation

Financing

- •Needs assessment of financial resources
- •Make changes in health and insurance law
- •Monitoring and evaluation of pc financing Standards
- •Develop home care and inpatient palliative care standards
- •Reflect pc issues in under and post graduate training curriculum for health professionals
- •Certification program in pc for doctors and nurses

Odontuya Davaasuren, Head palliative care association, Ulaanbaatar, d-odontuya@yahoo.com

Tsetsegdari Gombodoroj, Policy coordination department, Ministry of Health, mash@soros.org.mn

Bishindee Jonshin, Head of Health Insurance Department, State Social Insurance, info@ssigo.org

Gansukh Sandori, Deputy Director Government Implementing agency, gan@6676yahoo.com

The text and action plans from Croatia you can find to download from the web site www.eapceast.org. From Georgia we hope to have information in the next Newsletter.

Lets hear from you next year and until then

Merry Christmas and a Happy New Year

Sylvia Sauter

Carl Johan Fürst