EAPC news and views

www.eapcnet.org

The 3rd EAPC Research Forum – an update of a worldwide congress

It is exciting to see the 3rd EAPC Research Forum in Venice 2006, to be held on 25–27 May 2006, developing. It will be a good opportunity to hear the latest data, learn and collaborate, while also taking advantage of the relaxing and inspiring Venice atmosphere.

Five hundred and seventy-seven abstracts from 440 first authors have been submitted and will help to shape the forum. The abstracts come from 40 countries around the world, with the majority from Europe. Twenty-seven per cent of the first authors are from the UK; 37% from the Netherlands, Italy, United States, Canada, Germany and Sweden; 19% from Belgium, Switzerland, Australia, Ireland, Spain, and Norway and 43% of the abstracts were submitted from the other 27 countries. Physicians were first authors of 206 abstracts, nurses of 63, psychologists of 24, sociologists of 15, social workers of 11, and 'other' or 'not stated' professions authored all the others.

Currently, the abstracts are being reviewed by three (or exceptionally two) reviewers, who have been recruited from the invited speakers, the EAPC Research Steering Committee and the EAPC Board. Each abstract by nurses or physicians will be reviewed by at least one reviewer from the same profession, for the other professions the same procedure is intended, but the reviewers available may limit its feasibility. A big thank you goes to the reviewers, whose job is central to providing a high-quality meeting. The sessions are being organised by the Scientific Committee, with preparations under way from mid-December 2005, based on the reviewed and ranked abstracts. At the beginning of this year, the chairs and co-chairs of the free communication sessions will be invited to organise the sessions, prepare educational content and collaborate with the presenters of abstracts. Likewise, the poster presentation sessions will be planned to optimise the experience of presenting, visiting, collaborating and learning. A special session on abstract writing will be included in the program.

The scientific committee is grateful to all the invited speakers of the scientific and educational sessions who agreed to participate. The session chairs have already done a great job arranging sessions of both high scientific and educational value. There will be three preconference educational sessions, which will focus on the methodological, logistical and communication issues around research on symptoms, clinical trials and mixed methods.

The forum will be a place to meet new contacts, collaborate and receive educational experience, as well as information on new data and methods. The high number of abstracts suggests that the number of participants will be higher than in 2004. Since the forum benefits considerably from interaction among participants, emphasis is given to providing sufficient informal meeting rooms, get together possibilities, and opportunities to discuss with colleagues. Venice Lido is a great place to have a wander along the beach with your (new) colleagues or perhaps to enjoy a culinary delight. To strengthen the collaboration among EAPC groups and promote interested parties, two special sessions will focus on the EAPC Research Network Activities, and on the EAPC Task Forces. The focus on worldwide collaboration will be promoted by a joint session with International Association for Hospice and Palliative Care (IAHPC), introducing experts from all over the world who will discuss the problems of research in developing countries.

The next step is to register now please. You can take advantage of a reduced rate until 28 February 2006 so please register quickly! We look forward to seeing you in Venice.

Florian Strasser, Chair for the Scientific Committee, EAPC

Life directives or living wills

In the summer of 2005, the Directorate of Health in Iceland presented a new document within the area of patients´ rights, *Life Directives or Living Wills*. A living will or a life directive is an official standardised document where an individual has stated their wishes regarding treatment at the end of life, in case they become either physically or mentally unable to participate in such discussions. The document becomes valid only when the individual no longer is able to declare their will.

The main purpose of signing a life directive is to give individuals an opportunity to decide by themselves and to ensure a dignified death, and furthermore to enable relatives to accept the decision more easily. By signing the document, the individual has communicated their wishes regarding treatment at the end of life, such as treatment should not be started or continued when the hope of cure or palliation are no longer realistic. This is particularly relevant with regard to aggressive regimens or treatments that would only prolong the process of dying. Instead, treatment aimed at comfort and the best quality of life is emphasised. Moreover, the individual can define their position regarding donating organs or tissue for transplantation.

According to the laws on patients' rights from 1997, patients in Iceland can decide either to accept or reject a treatment. However, a living will or a life directive is not mentioned in that law, but their principles are in accordance with other laws and working traditions within the healthcare system in Iceland.

In the document two options are available: either the individual signs his wishes regarding treatment at the end of life or they designate a proxy. The proxy will then act on behalf of the individual and participate in discussions regarding treatment at the end of life – either to reject or accept treatment or to stop an ongoing treatment.

Four copies of the life directive are made and signed by two witnesses. One copy remains with the individual and one with the proxy; the third is sent to the Directorate of Health and is kept in a database accessible only by healthcare professionals and the fourth goes to the GP or another physician taking care of the patient. Signed life directives can be rendered invalid at any time. An example is available at the office of the Directorate of Health and on its website (available only in Icelandic).

Valgerdur Sigurdardóttir, Consultant in Palliative Medicine, Reykjavík, Iceland

Evaluation of the World Hospice and Palliative Care Day

The aim of World Hospice and Palliative Care Day (WHPCD) was to raise awareness of the need for hospice and palliative care across the world. The International Observatory on End of Life Care have been asked by Help the Hospices (www.helpthehospices.org.uk) to evaluate the first ever World Hospice and Palliative Care Day. The purpose of the evaluation is to measure the impact of WHPCD on hospice and palliative care around the world, and to identify and describe events and activities that have been particularly successful.

As part of the evaluation process, an electronic questionnaire is being circulated throughout global hospice and palliative care networks asking individuals and organisations about their experiences and views of WHPCD. The opinions and experiences of people who actively organised for the day are very important. The results of the questionnaire will be included in an evaluation report published at the end of January 2006 and will be used to help plan future World Days.

The questionnaire should take no more than 15 minutes and the information given will be treated confidentially. Completed questionnaires should be submitted to Dr Liz McDermott at the International Observatory on End of Life Care, Lancaster University UK. To complete one please visit: www.eolc-observatory.net/phpQ/fillsurvey.php?sid=6

WHPCD – the Belarus experience

Although palliative care and the hospice movement are relatively young in the Republic of Belarus – the first hospice in the country, the Belarus Children's Hospice, only opened in 1994 – Belarus was looking forward to the WHPCD on 8 October 2005. The event turned out to be particularly special as it crowned the 3rd International Conference on Palliative Care for Children that was held in Minsk, 5–7 October 2005.

The day took place in the City Pushkin Library and united more than 250 people from Belarus, Russia, Latvia, Austria, Switzerland, Germany and other countries. The aim was to draw attention to palliative care, so everyone interested was invited to join the celebrations.

The programme was diverse with some national elements, such as a music concert, a folk art exhibition, a festive lunch and an excursion to the Belarus Children's Hospice, which is situated in the outskirts of Minsk.

The turning point of the day was negotiations with major Belarusian businessmen aimed at improving the funding situation and finding new ways of providing support to the hospices.

Hospice leaders hope that these negotiations will contribute to the development of the hospice movement and palliative care in Belarus and the WHPCD will draw public attention to hospice issues and perspectives.

Anna Garchakova, Belarus Children's Hospice, Minsk, Belarus

What is The Bereavement Register?

The Bereavement Register is a service with one simple aim: to reduce the amount of direct mail sent to those who have died and consequently make the passage of bereavement that little bit easier.

Our names and addresses appear on many databases and mailing files which means, unfortunately, that we are often bombarded with mail we just do not want. Imagine if that mail is sent to a family member of someone who has recently died. The distress and upset that can cause to others is immeasurable.

From our own personal experiences, we understood there was a need to provide a solution to this ever increasing problem. So, in 2000, The Bereavement Register was launched as a service specifically designed to remove the names and addresses of people who have died from databases and mailing files. Coming to terms with the loss of a relative or friend takes time. You will want to remember the good times you shared with fondness and not be bombarded or bothered by direct mail sent to a loved one who has recently passed away. Mail of this kind serves no purpose so we can help put an end to these sad reminders.

If you would like information on our free service currently available in the UK, Canada (in English and French) and France, please contact us on +44 1732 460000, write to us at The Bereavement Register, FREEPOST, Sevenoaks, Kent, TN13 1YR, UK or visit www.the-bereavement-register.org.uk