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5th Research Forum of the EAPC puts emphasis on original material

The 5th Research Forum of the European Association for Palliative Care (www.eapcnet.org/Research2008/Index.html) will take place from 29–31 May in Trondheim, Norway, giving recognition to the resources Norway has allocated to the development of research in palliative care and to the relevance of the achievements made in the field by our Norwegian friends and colleagues in the past ten years. We now have 513 abstracts submitted from 38 countries, including Asian and African countries (see Table 1).

The programme includes a few themed sessions with a broad and multidisciplinary approach, which have been planned by the scientific committee. However, most of the space for presentations has been reserved for original submitted materials, which will be judged on their originality and scientific value by an extended advisory board with more than 50 international experts. Some of the original submissions will also be chosen for plenary presentation in order to motivate those conducting new and important research to participate in the conference, at which it is hoped all research groups and individuals will be given the opportunity to make their data visible and open to discussion and debate.

Scientific merit will be the only criterion by which the scientific committee and the advisory board judge entries. It is obvious that mistakes will be made and that the scientific committee and the organising committee will be criticised for them. We are happy to take on that challenge and to establish an open process in the tradition of the Research Forum, with the aim of improving through learning from our mistakes and from the suggestions of our peers.

The topics already in the programme range from research into end-of-life care to translational research in opioid analgesia genomics. The abstracts received cover the full range of interest of palliative care (see Table 2).

Table 1. Countries that have submitted abstracts so far

Country	Number of abstracts	Country	Number of abstracts
Argentina	2	Israel	8
Australia	4	Italy	25
Austria	13	Japan	2
Belgium	23	Kenya	2
Bosnia and		Lebanon	2
Herzegovina	2	The Netherlands	34
Brazil	3	Norway	25
Bulgaria	1	Poland	15
Canada	22	Portugal	4
Colombia	1	Russia	3
Czech Republic	1	Saudi Arabia	1
Denmark	8	South Korea	1
Finland	1	Spain	22
France	4	Sweden	12
Georgia	2	Switzerland	12
Germany	40	Taiwan	2
Greece	2	Uganda	1
Hungary	1	United Kingdom	147
Iceland	2	United States	45
Ireland	18	**Total number**	**513**

Table 2. Abstracts by category

Trondheim 2008 topics/categories		Number of abstracts received	Number of abstracts to come
Symptoms	Pain	57	11
	Dyspnoea and breathlessness	13	1
	Fatigue and cachexia	28	1
	Cognitive symptoms and delirium	5	1
	Other symptoms	39	2
	Subtotal	**142**	**16**
Topic areas	Assessment and measurement tools	58	12
	Audit and quality control	33	4
	Basic and translational research	6	1
	Bereavement	3	2
	Evaluation of education programmes	16	-
	End-of-life care and quality of death	62	11
	Epidemiology	7	2
	Ethics	22	-
	Family and carers	17	1
	Medical sociology	8	1
	Psychology and communication	19	1
	Research into organisation of services	30	6
	Research into policy	12	3
	Research methodology	27	7
	Subtotal	**320**	**51**
Specific pathologies and patient groups	Cardiopulmonary diseases	4	-
	HIV/AIDS	3	-
	Neurological disorders	4	-
	Other non-cancerous diseases	8	1
	Palliative care in children and adolescents	14	3
	Palliative care in the elderly	17	3
	Subtotal	**50**	**7**
	Total	**512**	**74**

Cicely Saunders's idea of a 'type of research that has never been seen before' informed our thoughts in building this programme. We believe that palliative care, with its joint interest in the patient as a person and the professional development of appropriate care instruments, is the only area of medicine where science covers the full range of human needs in chronic disease and in the terminal phase of illness from basic care to sociology and pharmacology.

We believe that the Trondheim Forum will provide a gathering for an enthusiastic group of people who share an interest in, and a passion for, their jobs and their patients, and that the clear Nordic sky and the midnight sun will be an inspiration for their friendship ■

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Christian mission set up team to spread palliative care education in Kenya

In January 2007, Mission Opportunities Short Term (MOST), a Christian voluntary organisation in Ann Arbor, Michigan, USA, decided to set up a multidisciplinary team comprising eight palliative care specialists from different US palliative care and hospice organisations and Dr Vilnis Sosars from Latvia. The aim of the team was to organise an educational seminar at Kisumu, in the western part of Kenya, from 18–23 September 2007.

The preparatory work involved recruiting appropriate palliative care specialists. These were a doctor, a nurse, a specialist in psychosocial work, a specialist in complementary therapy, a volunteer co-ordinator, an occupational therapist, a hospice pastor and a deaconess.

The team had to prepare an educational programme covering specific palliative care problems in Kenya. They wrote and printed the syllabus, which included a large variety of topics (see Box 1).

All the preparatory and organisational work for the seminar by the MOST team for Kenya was voluntary.

The MOST team's aims were:

1) To present standards for, and to show the essence and meaning of, palliative care
2) To analyse the incidence of mortality and the situation of palliative care in Kenya
3) To organise teaching sessions for local co-ordinators (about 50 people from five dioceses) or people with a particular interest in palliative care
4) To consult patients
5) To help others to understand the basics of palliative care and pain control, to disseminate knowledge of, and experience in, palliative care, and to encourage the provision of day- and home-care facilities.

According to the 2007/2008 Human Development Report, Kenya ranks 148 out of 177 countries worldwide.[1] It is 19th out of 45 in African countries (2006) and has 32 million inhabitants. Kenya is regarded as the most HIV/AIDS-affected country in Eastern Africa. Up to 1.7 million people live with HIV/AIDS: 10% of people in urban areas and 5–6% of those in rural regions are affected by it. About 200,000 people died from HIV/AIDS (2003). Between 65 and 70% of HIV/AIDS patients develop different cancers.[2]

The MOST team's analysis revealed that the real number of cases of HIV/AIDS, cancer and tuberculosis in Kenya is much higher than that reflected in official available references. Despite that, knowledge of pain and symptom control in these diseases is vague.

Kisumu, where the team operated, is a town of 150,000 inhabitants. There was already some provision for day and home care. People who were involved in palliative care in the eastern part of Kenya were properly trained to perform home- and day-care work by the MOST team members.

Box 1. Some of the topics covered by the MOST syllabus

- An interdisciplinary approach to patient care, education and training
- Pain management
- Other symptom control in HIV/AIDS
- Forgiveness and reconciliation
- Grief
- Spiritual assessment
- Stages of dying
- Bereavement
- HIV/AIDS and nutrition
- Water and food safety and hygiene
- Pressure ulcers
- Roles of a volunteer and ethical considerations
- Complementary therapies
- Psychosocial needs of patients and families
- Emotional and mental symptoms of the dying patient
- Children and care-giving
- Lightening the burden of care
- Dealing with dementia
- Spiritual support

A day care centre had been planned for Kisumu this year, but the current political unrest in the country may result in a delay. The MOST team's activities were supported by the Lutheran Church of Kenya ■

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2. Wright M, Clark D, Hunt J, Lynch T. *Hospice and palliative care in Africa: a review of developments and challenges.* Oxford: Oxford University Press, 2006: 101–127.

US radio host devotes programmes to empowering patients and their families

Patient Power is a service based in Seattle, USA, and founded by two health communications pioneers, Andrew and Esther Schorr, who believe that knowledge is the best medicine. They previously founded HealthTalk, a website that provides support for people with chronic illnesses and cancer.[1] Patient Power is devoted to giving patients the knowledge to help them and their families to get the best medicine and return to good health.

Patient Power, which began in February 2005, is hosted by Andrew Schorr, patient educator and advocate. It includes an hour-long live talk show every Sunday on radio and online as well as several online talk shows throughout the week. Patient Power features renowned medical experts on topics that include cancer, pain, palliative care and diabetes, as well as heart specialists, top pharmacists and experts in clinical trials. The show brings together patients in a radio and internet community to help navigate an often inhospitable healthcare system. Patient Power takes questions from callers and internet listeners on topics such as how to find the right doctor, how to advocate for patients effectively, when to get a second opinion from a specialist, how to evaluate one treatment option over another, and so on.

Patient Power is built on Andrew Schorr's two weekly radio programmes, one nationally syndicated and one in Seattle. They can be heard live on the web, and past programmes can be found on the website replays page.

Andrew Schorr, host of Patient Power

Andrrew Schorr is a former television news reporter, a producer for national television and, since 1985, has been a pioneer in health communications.

In 1996, following a routine blood test, Schorr was diagnosed with a lymphocytic leukaemia. By reaching out to other patients and connecting with doctors who specialise in his illness, he participated in a clinical trial, received 'tomorrow's medicine today' and now, nine years after diagnosis, remains in remission and takes no medicines.

Andrew's aim is to help patients and family members learn more about their health concerns so they can make informed decisions and feel in control. Patient Power services are a reflection of his passion. He is committed to helping each person he encounters to approach their illness in a way that gives them the best chance of good health: becoming informed about their diagnosis, seeking out the best healthcare providers, getting second and even third opinions on what approach to take, and drawing on others for support ■

Visit Patient Power at: www.patientpower.info/
Andrew's Blog, where you can make comments or ask questions, is at: www.patientpower.info/blog/default.asp
To search Patient Power replays by health topic, medical expert or date, go to: www.patientpower.info/programreplays.asp
For forthcoming programmes, webcasts and events, go to: www.patientpower.info/upcoming.asp

Reference
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