The European Association for Palliative Care

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Introduction

Thanks to the initiative of Professor Vittorio Ventafridda and the Floriani Foundation, the European Association for Palliative Care (EAPC) was founded by 42 members on 12 December 1988. The organization had the following aims:

- Increase awareness and promote the development and dissemination of palliative care at scientific, clinical and social levels.
- Promote the implementation of existing knowledge, train those who at any level are involved with the care of patients with incurable and advanced disease, and promote study and research.
- Support and give patronage to scientific and educational events promoting the dissemination and development of palliative care.
- Promote and sponsor publications or periodicals concerning palliative care.
- Bring together those who study and practice the disciplines involved in the care of patients with advanced disease (doctors, nurses, social workers, psychologists, and volunteers).
- Unify national palliative care organizations and establish an international network for the exchange of information and expertise.
- Address the ethical problems associated with the care of terminally ill patients.

Structure of the EAPC

EAPC Membership

Due to the varying levels of palliative care in Europe, the EAPC accepts individuals as well as organizations and associations. In the first quarter of 2002, the EAPC counted about 200 individual members from countries all over the world and about 240 representatives of 27 associations from 18 different European countries. The latter associations join the EAPC as collective members. These national and regional associations represent approximately 50,000 persons working in or supporting Palliative Care.

General Assembly

The General Assembly comprises all members of the Association and meets at least once a year to approve the accounts, the budget, and the activity reports, confirm the general policy of the Association, and approve internal rules. The General Assembly appoints the Board of Directors every 4 years.

Board of Directors

The Board of Directors is composed of 13 members (see www.eapcnet.org/about/board.html). They meet 4 to 5 times a year to decide about general management of the association.

EAPC Head Office

The day-to-day management of the EAPC is run by the Executive Officer, Heidi Blumhuber, assisted by a secretary. She collaborates closely with the president, currently Dr. Stein Kaasa; the Secretary, Dr. Carlo Peruselli; the treasurer, Dr. Silvio Necchi; and the Honorary Director, Dr. Franco De Conno. Since 1990, the Head Office of the EAPC has been based at the National Cancer Institute of Milan in the Division of Rehabilitation and Palliative Care. In the last year, the work for the EAPC Congress activities have grown extensively. Therefore, the Board of Directors has recruited a Congress Officer, Antonella Lio, to the Head Office.

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Office. She is responsible for congress organization of the EAPC.

**EAPC’s Communication**

EAPC Web Site (www.eapcnet.org)

The web site has become a crucial communication tool to update the membership and others on the latest developments. All activities of the EAPC are reported in detail. It also contains news and publications from the collective members and includes a list of Palliative Associations in the World. Since its creation in 1999, the EAPC web has been accessible without any registration. The EAPC decided to implement an access with registration and passwords for a certain number of sections during 2002.

The European Journal for Palliative Care (EJPC)—Hayward Medical Publisher

EJPC is the official journal of the EAPC. It is a multidisciplinary journal, published 6 times a year in both English and French. EJPC is a review journal and is therefore not designed to publish original research articles. Commissioned review articles cover all aspects of the care of patients with advanced, incurable diseases, and contributions are welcomed from members of every discipline involved in palliative care. EJPC is available only by subscription. EAPC members can subscribe at a special rate. The content of the latest issue, an article index, and a list of back issues is available on the Internet. For more information, see www.eapcnet.org/about/ejpc.html, which also includes a link to the Spanish translation of the abstracts published on the Web site of the Spanish EAPC Collective Member SECPAL.

EAPC News and Views

EJPC also contains the EAPC News and Views, which are regularly available as downloadable files in English and French on the EAPC web site at www.eapcnet.org/publications/news.html. Also, the EAPC news is published in Spanish on the Web site of SECPAL.

**EAPC Projects**

**Task Forces**

The strength and influence of the EAPC depends upon the contribution and activity of its members. One year ago, the EAPC decided to channel the activities into focused areas and established the principle of task forces on different issues. Members and Collective Members may make proposals for topics of projects to be covered by a task force, which will be considered by the Board. Details are published on www.eapcnet.org/projects/projects.html.

*Ethics Task Force.* The question of ethics in palliative care is one at the forefront of every palliative care professional’s mind. In 1991, a debate at the European Parliament to adopt a document on the legislation of euthanasia stimulated discussion at all levels in Europe. The Board of Directors decided to clarify their position towards euthanasia. A document was published in the first issue of EJPC, launched in 1994. The Board of Directors (1999–2003) felt that it was necessary to review this document and decided to constitute a task force to work on the issue palliative care and euthanasia and to revise the position paper. The group is chaired by Lars Johan Materstved. It has met twice since the 7th EAPC Congress and has finalized a paper that was presented to the EAPC Board of Directors for comments in April 2002. Details are published on www.eapcnet.org/projects/ethics.html.

*Palliative Care and the Elderly.* Dr. Vittorio Ventafridda has taken the initiative to host and organize a working party on Palliative Care and the Elderly on behalf of the Floriani Foundation, as a collaboration project with WHO and EAPC. An international working group has been established, chaired by Irene Higginson and Vittorio Ventafridda, with representatives from Europe and North America. One of the aims is to publish a review/state of the art and recommendations on the topic. Marilene Filbet, EAPC Board member, has proposed an EAPC task force to follow up the above-mentioned meeting.

*Education in Palliative Care.* The Board has very recently received one proposal and one request for task forces in the area of education and has constituted a committee to look into the details.

*Eastern Europe*

One of the priorities of the EAPC for the future is to support the development of palliative
care in Eastern Europe. In 2001, an EAPC coordination center was established at Stockholm’s Sjukhem Foundation in Stockholm, Sweden. This foundation is linked to the Karolinska Institute and locally supports the center. Through a grant from the Open Society Institute, it has been funded for two years. The director of the center, Dr. Carl Johan Furst, and the center coordinator, Sylvia Sauter, are responsible to the EAPC Board of Directors.

The first priority of the coordination center was to survey palliative care needs in different countries. Results point to high priority for activities related to education and training, and legislation and policy questions among politicians, professionals, and the public. A network of contacts and initiatives is currently growing. The Center has launched a Web site, www.eapceast.org, which is linked to the EAPC Web site.

Research Network

The EAPC considers research a key issue for the future of palliative care. In 1996, Dr. Franco De Conno was nominated to create and chair a steering group with the aim of establishing a research network. When the Research Steering Committee (RSC) first met, it felt it was premature to establish a network with the aim of carrying out multicenter and multinational studies. They decided to make use of the considerable information and knowledge that already existed among palliative care experts to create a common language and common approaches.

To date, the RSC has organized nine expert working groups on a variety of topics for which a common European position or recommendations are needed. For these, expert groups were invited from various fields in addition to the RSC members. The results of the work of six groups have been published by April 2002 and two further papers are in progress. More information and some publications are published on the EAPC Web site at www.eapcnet.org/researchNetwork/research.html.

The RSC also proposed specific panels and seminars for the 5th, 6th, and 7th Congress of the EAPC and other conferences. It organizes a specific small conference on research for selected groups interested in research in the years between the biennial EAPC Congresses.

In 2000, the RSC organized its first empirical multicenter study, a one-day, cross-sectional survey. The study included 21 countries—all the 15 member states of the European Union as well as Norway, Switzerland, Iceland, Israel, Romania, and Cyprus. The two main aims were to create a network of European palliative care centers and services, to introduce them to collaborative research, and to obtain descriptive data of the practice of palliative care across Europe. One first paper has been circulated to the writing committee. They are in the process of analyzing the data sets for a further 3 papers.

EAPC Congresses

Every second year, the EAPC organizes a European Palliative Care Congress. The biennial congresses of the EAPC have become one of the highlights of the palliative care calendar, offering opportunities for networking, for keeping in touch with latest developments, and for renewing enthusiasm and energy for the work.

Past Congresses

The congresses have been held in the following countries:

- 1st EAPC Congress—Paris, October 1990: 1,630 participants from 23 countries
- 2nd Congress—Brussels, October 1992: 1,300 participants from 27 countries
- 3rd Congress—Bergen, June 1994: 501 participants from 27 countries
- 4th Congress—Barcelona, December 1995: 1,663 participants from 45 countries
- 5th Congress—London, September 1997: 2,500 participants from 48 countries
- 6th Congress—Geneva, September 1999: 2,355 participants from 43 countries
- 1st Congress on Research of the EAPC Research network—Berlin, December 2000: 350 participants from 40 countries
- 7th Congress—Palermo, Italy, 1–5 April 2002: 1,850 participants from 45 countries
- 2nd Congress on Research—Lyon, 23–25 May 2002: 525 participants from 36 countries.

The reports of these congresses can be viewed at www.eapcnet.org/congresses/previous_cong.html

The feedback from the last congress is at www.eapcnet.org/congresses/cong_followup.html.
Next Congresses

The abstracts can be downloaded from the EAPC web site (www.eapcnet.org/congresses/lyon2002.html).

8th EAPC Congress—The Hague, 2–5 April 2003. The Scientific Committee has decided to include nine plenary sessions, covering key aspects of palliative care and its development. Each plenary session will be followed by a parallel session organized as a discussion panel, allowing both speaker and audience to discuss the topic in more detail. A “rapporteur” will give a formal response to the plenary lecture and two independent specialists will then give their statements on the topic. Thereafter a general discussion will follow. The Scientific Committee, chaired by Dr. Stein Kaasa, hopes that this initiative will bring extended opportunities for discussion into the congress. Special attention also will be given to the issue of “palliative care and older people”—reflecting the consequences and demands of an aging population on palliative care services. The EAPC expects between 1,800 and 2,500 participants. The congress is organized in collaboration with the Dutch collective member NPTN. During the congress, the participants will be given the opportunity to acquaint themselves directly with the development of palliative care in The Netherlands through on-site visits. Please visit the congress web site for more information (www.eapcnet.org/TheHague2003/).

3rd Congress on Research—Italy, Spring 2004. The Board has recently approved the proposal of the Research Steering Committee to hold the next conference in Italy, in 2004.

9th EAPC Congress—2005. The 9th EAPC Congress will be held in Eastern Europe.