

Report of the European Association for Palliative Care

Heidi Blümhuber, Franco De Conno, MD, and Geoffrey W. Hanks, MB, BS
European Association for Palliative Care (H.B., F.D.C., G.W.H.), National Cancer Institute (F.D.C.), Milan, Italy, and Department of Palliative Medicine, (G.W.H.) Bristol Oncology Center, Bristol, United Kingdom

Introduction

The European Association for Palliative Care (EAPC) Head Office is situated within the National Cancer Institute in Milan. All activities are coordinated at this Head Office, which collaborates closely with the EAPC President and keeps the Board of Directors regularly informed of all activities. The Board of Directors meets twice each year with the Head Office to assess developments, discuss problems, and decide future strategies. The General Assembly is convened every 2 years concomitant with the biannual EAPC congresses. During the Fourth General Assembly, which was held during the EAPC's Fourth Congress in Barcelona, Spain in December 1995, the members of the Board for the next 4 years were elected. These officers include President: Geoffrey Hanks; Vice Presidents: Bernadette Wouters, Jordi Roca i Casas, Charles Henri Rapin; Secretary: Carlo Peruselli; Treasurer: René Schaefer; Members: Michèle Salamagne, Friedemann Nauck, Frances Sheldon, Tony O'Brien, Annetie Welshman, Carl Johan Furst, Verena Luchsinger. Vittorio Ventafridda was nominated Honorary President of the EAPC. The Executive Officers are Heidi Blümhuber and Franco De Conno.

Some Figures About EAPC's Development

EAPC development reflects the rapid growth of palliative care in Europe over the

past 4 years. Due to the incompletely consolidated situation of palliative care in some countries, the EAPC is actually both a federation of organizations and an association with individual members.

The EAPC was created by 42 founding members from nine European countries. It developed slowly but steadily until 1991, reaching 433 members. A big step forward in its development occurred in 1992, when it was decided to admit National Associations as collective members. By the end of 1995, EAPC counted ten collective Associations, which represent 7016 members. Together with the individual members EAPC has a total number of about 7584 members from 28 European countries and 24 non-European countries. In view of the ten pending requests for collective membership, an increment of 4000 members is foreseen.

In total, EAPC established liaisons and collaborations with 27 National Organizations and Associations that are operating in the field of palliative care in Europe and with 12 others in non-European countries. EAPC is also involved with other international organizations, including the International Association for the Study of Pain (IASP); the World Health Organization (WHO), for which the liaison officer is Prof. Vittorio Ventafridda; and the European School of Oncology, for which the liaison officer is Dr. Franco De Conno.

EAPC maintains the following directories, which are regularly updated:

- Database of persons involved or interested in palliative care, with respective address, profession and specialty; this resource

Address reprint requests to: Heidi Blümhuber, EAPC, National Cancer Institute, Via Venezian 1, 20133 Milan, Italy.

reached 14,000 in February 1996.

- Directory of organizations and associations in the field of palliative care and of organizations of specialties that should be connected with palliative care.
- Directory of official documents on subjects regarding palliative care.

EAPC Activities

Biennial Congresses

The first congress was held in October 1990 in Paris, France. The major aim of this congress was to obtain the best media coverage possible, in order to spread information about the Association and palliative care. About 50 journalists were present during these 3 days of work. More than 30 French and European journals and magazines published articles, or even "dossiers" about palliative care. All French television channels and several radio stations reported this important event. The 1700 active participants came from 23 countries and 13 different professions.

The second congress held in Brussels, Belgium, in October 1992 was attended by 1300 participants in varied professions from 27 different nations. The major aim of this congress was to offer a more detailed and specific educational program and stimulate and encourage all health-care professionals involved in the field. Pre-teaching sessions were foreseen in the program.

The third congress was held in Bergen, Norway, in June 1994. There were approximately 501 participants from 21 European and 6 non-European countries. This congress was developed as a more specialized meeting. In this country with a relatively small population, media coverage was not to be expected. Participation was particularly from Norway, United Kingdom, Sweden, Italy, Belgium, Germany, France, Spain, Switzerland, and eastern countries.

The fourth congress was held in Barcelona, Spain, in December 1995. This was the first Congress of the EAPC organized at the same time as the Congress of the National Association (SECPAL). For the EAPC part, a previous survey on topic suggestions had been made and more than 200 international experts had sent their proposals, many of which were

included in the program. The program included a total of 218 speakers from 23 countries and 13 different professions; they gave 14 keynote addresses and 285 different lectures in 110 sessions. The total abstracts submitted were 539, of which 433 were accepted as posters and 49 included in the program as oral presentations. A new feature of this EAPC Congress was a concluding session presented by 14 rapporteurs, who prepared approximately ten main points for the 14 different headings. These headings included special aspects of palliative care in oncology, in geriatrics, in acquired immunodeficiency syndrome (AIDS), and in pediatrics. There were about 1663 participants from 45 countries and five continents. The official languages were Spanish, English, and French, for which simultaneous translation was available.

The fifth congress of the EAPC will be held at the Barbican Center in the City of London from 10–13 September 1997. The congress will be hosted by the APMGB and the Association for Palliative Medicine of Great Britain and Ireland under the chairmanship of Dr. Ilora Finlay from Cardiff. The Organizing Committee, chaired by Dr. Anne Naysmith of London, and the Scientific Committee led by Frances Sheldon of Southampton have already started work. Abstracts will be invited for both oral and poster presentations, and a preliminary program will be available in Spring 1996.

The sixth congress will be held together with the Swiss Society for Palliative Medicine in Geneva (Switzerland) in 1999 and will be entitled "100 days before the year 2000."

Expert Groups

Apart from Biennial Congresses, EAPC organizes meetings of specialists and expert working groups concerned with controversial aspects of palliative care. The first two groups, which started with consensus meetings held in Palermo in 1992, worked on the following topics:

1. Modes of administration of morphine in cancer pain. The guidelines of this working group were published in the *British Medical Journal*, 30 March 1996, Vol 312, pp 823–826.
2. Nutrition and hydration in patients with advanced cancer. The results of this meeting were published in *Nutrition* 1996; 12(3):168–172.

During March 1993, a grant and the support of the program "Europe against Cancer" of the European Community encouraged EAPC to organize a "workshop to study the feasibility of a training programme in palliative care for physicians in Europe." Thirty-two experts from the 12 European Community member states and Sweden met in Brussels and elaborated a report and recommendations. These were published and distributed by the EAPC under the aegis of the "Europe against Cancer Programme" to all deans of the faculties of medicine all over Europe.

A third consensus meeting was held in Athens in 1994 on "Guidelines on the Management of Bowel Obstruction for Cancer Patients for Whom All Available Oncological Therapies for Tumor Control Have Been Exhausted." A final paper will be ready for submission in 1996 to a pertinent medical journal.

Publications

The EAPC has its own newsletter; this information bulletin is distributed to all caregivers interested in palliative care. The first newsletter was published in the Spring of 1989. Semi-annual publications followed. By the end of 1993, the EAPC mailing list had grown to over 12,000 addresses reaching both European and non-European countries.

In Spring 1994, the European Journal of Palliative Care (EJPC), the official quarterly journal of the EAPC, was launched. At the same time, the EAPC began quarterly publications of its newsletter, which is included in the EJPC and is distributed to all EAPC members. The EJPC is a review journal. Commissioned review articles cover all aspects of the care of patients with advanced terminal disease. It is published simultaneously in English and French, and is designed to be of direct and practical relevance to professionals.

Apart from the periodic publications, EAPC has published two reports on the status and development of palliative care education in 1992 and 1994. A practical manual on palliative care was edited in Italian in 1993, and a second version was completed in 1994. Seventy thousand copies of this manual have been dis-

tributed. Due to the success and demand for this booklet, an updated translation in English is being prepared for 1996.

Projects

Three important networks, working in close collaboration with the Head Office, were set up in 1995. The first one is the Education Network, the purpose of which is (a) to emphasize collaboration with the already existing education initiatives, (b) to develop and improve the procedure of evaluation of the existing initiatives of palliative care courses and apply the program of the EAPC patronage, (c) to draw up a directory of education initiatives and another one on educational materials, and (d) to develop the "twinning-project" between services and create a directory of twinning services.

The second is the Ethics Network, whose primary objective is to address the controversies surrounding palliative care versus euthanasia. This network will seek to develop a plan of action pertaining to this issue in Europe.

The third is the Research Network, which aims to bring together the already active palliative care centers with the foremost purpose of setting up multicenter controlled studies. The chairperson expects the members of the Network to suggest controversial issues in palliative care that require discussion by expert groups. The headquarters are in contact with SAMOT and the Ettore Majorana Center, Italy, which will support the first two meetings of the steering committee of this Network.

In collaboration with the headquarters of its collective members, the EAPC Head Office intends to draw up the following directories: (a) database of palliative care services, hospices, home-care teams in Europe; and (b) directory with basic comparable information regarding the implementation of palliative care in European countries.

Finally, and following the suggestion of the collective member "Société Française pour l'Accompagnement et les Soins Palliatifs," the EAPC made an application in 1996 to become a nongovernmental body of the Council of Europe.