# NEWSLETTER

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EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

## MORE REPORTS FROM THE EAPC 1999 CONGRESS IN GENEVA:

### Hellenic Society of Palliative and Symptomatic Care of Cancer and non-Cancer Patients (HSPSC)

*Athina Vadalouca, President*

This society was established in November 1997, with 101 founding members. Full members include Greek physicians, graduates of medical schools in Greek and foreign universities with a scientific or professional interest in our objectives, health carers, social workers, nursing personnel, psychologists, legally qualified individuals and legal organisations of a mainly medical character, pursuing similar objectives to those of the society.

The HSPSC's main objective is improving the quality of life of patients suffering from cancer, AIDS, brain injury and cerebral strokes, as well as palliative therapy and symptomatic care for elderly patients.

We have already organised the first Pan-Hellenic Congress of Palliative Care, in Athens, December 1998, with international participation. The congress was a great success, with more than 400 participants, and prompted 80 new applications for membership.

The HSPSC, in cooperation with other organisations such as the Greek Cancer Society and the Pain Society, has arranged lectures, round tables and seminars in Athens and other cities to spread knowledge and awareness of palliative care. Last month, the HSPSC's president published a book on palliative care, *Palliative and symptomatic care for patients in terminal stages*, which will be used for teaching at the University of Athens.

### Israeli Association of Palliative Care (IAPC )

*Ora Cibulski, President*

This association was founded in February 1993 and now has about 100 members.

#### Definitions and objectives

The Israeli Association of Palliative Care (IAPC) defines palliative care as total care of the terminally ill patient when the disease no longer responds to curative treatment, and the control of pain, other physical symptoms and social, psychological and spiritual problems is paramount. Although palliative care is not disease- or age-specific, in Israel most patients who receive palliative care are elderly or have cancer.

Palliative care is multidisciplinary in its approach and encompasses patient, family and community. It offers the most basic concept of care, that is, providing for the needs of the patient and family in the home, hospital or hospice. Palliative care affirms life and regards dying as a normal process; it neither hastens or postpones death. It sets out to preserve the highest quality of life until death.

Membership of the IAPC is on an individual basis. Members may be professionals from any discipline engaged in palliative care, volunteers who have completed a hospice volunteer training programme, or lay persons that support the principles of palliative care.

The IAPC has the following objectives:

- To represent professional and trained volunteers who care for dying patients and their families
- To encourage meetings and discussions between professionals from many disciplines and between public institutions and government agencies involved in the care of dying patients
- To promote the knowledge and practice of palliative care at the scientific, clinical and social level
- To develop training programmes, continuing education and university curricula in palliative care for a variety of professions
- To publish information on the dying patient to all professionals, organisations and the public
- To encourage research, auditing and evaluation of programmes and projects about dying patients and palliative care
- To provide a platform for the analysis and discussion of ethical problems and difficult issues
- To contribute our experience and professional knowledge to health and welfare policy, the development of new services, and laws on the rights of dying patients and their families
- To develop ties between the IAPC and similar associations abroad, and to establish international networks for the exchange of information and expertise.

Some of these objectives have been achieved but most are still in progress and demand constant attention.

### Fédération JALMALV (Jusqu'à la mort, accompagner la vie)

*René Schaerer, President*

JALMALV is a voluntary organisation, founded in Grenoble, France, in 1983. Our association's name, 'Accompanying life up until death', has two meanings: not hiding from death or fearing to name it, and being ready to accompany life to the end, providing quality of life to those approaching death.

The movement's main aim is to promote better care for the dying, whether at home or in institutional care, through a greater awareness of their needs, by providing more information on symptom control and palliative care in terminal illness and offering greater support for carers, families and friends.

We also aim to contribute to the development of changed attitudes towards death and dying in society. As we have discovered in our 16 years' experience, this is a major issue for society, where traditional solidarity with the dying and their families has gradually declined.

Our work consists of organising regular meetings, lectures and debates, as well as local workshops on support for the dying and changing attitudes in the caring professions and among the general public. We also provide courses in listening and counselling, touch and massage, understanding bereavement and the specific demands of terminal care. Small teams of volunteers accompany the sick in hospitals and homecare units.

The selection and training of volunteers is very demanding. All JALMALV volunteers undertake in-depth training in listening, basic information on the issues of dying and palliative care, and the needs of patients and their carers. They also receive regular support and counselling.

Members are often asked to give talks on aspects of these problems and these lectures have led to the founding of new associations in other parts of France.

The Fédération JALMALV, established in 1987, now comprises 57 local associations with about 4,400 subscribing members and twice as many supporters. Local associations are managed by 550 volunteers who are members of the local boards. About 500 volunteers are involved in 'accompaniment', 175 of whom are in home support teams. Another 400 are in training.

The Fédération JALMALV is supported by the Fondation de France, which has enabled it to organise national workshops for members on major issues in accompaniment. These workshops take place throughout France, and deal with the training, support and coordination of volunteers, volunteer support in the home, accompanying the elderly, talking about death with children and adolescents and bereavement counselling.

Other workshop topics include accounting for association treasurers, communication skills for group leaders and the philosophy of palliative care.

The Fédération JALMALV holds an annual conference entitled 'Les Journées Nationales'. Topics at previous conferences include accompanying the elderly (1998) or dying at home(1999).

The Fédération's headquarters are in Paris, where it shares facilities with JALMALV Paris/Ile de France. We publish a quarterly review in French, *Revue de JALMALV*, first printed in 1983. Each issue is devoted to a special aspect of care for the dying.

The Fédération JALMALV was a founding member of the Société Française d'Accompagnement et Soins Palliatifs (SFAP) and is a member of the European Association of Palliative Care (EAPC). On a national and international level, it shares the aims and ethics of these two organisations.

## The Cypriot Association of Cancer Patients and Friends (PASYKAF)

*Anna Achilleoudi, President*

The Cyprus Association of Cancer Patients and Friends (PASYKAF) is a registered charity, first established in 1986. Its main activities are providing information on, and improving public awareness of, the prevention and early detection of cancer.

Education and training for medical, paramedical and nursing staff has been a continuing role of the association, as well as targeting areas that improve quality of life for cancer patients and their families.

In Cyprus, no community care is provided by the state for incurable illness. Palliative care services began in 1992 when PASYKAF established a homecare service in the capital. Today, this service is available throughout most of the island.

The team consists of trained nurses, part-time doctors, physiotherapists, psychologists, social workers and volunteers. The service has progressed and expanded through staff's commitment to improve their knowledge and skills in the fields of pain, symptom control and psychosocial support to the patient and their family.

Over the last seven years, we have improved our understanding of the patient's needs, and what needs to be achieved to improve and maintain high standards of palliative care.

We have formed a special group to focus on developing palliative care services and be actively involved in caring for people with terminal disease, focusing on cancer. Within the group, which is under the umbrella of PASYKAF, we have a working party made up of palliative care nurses, anaesthetists, oncologists, pharmacists and a psychologist.

The group's first project was to prepare a proposal for the government to increase the availability of drugs needed for cancer pain management. This is now being processed and the group will continue to use evidence-based information to select other drugs needed for symptom control, such as specific antiemetics or laxatives.

The group will also try to obtain authority from the government to store controlled substances on PASYKAF premises for use in the homecare setting. The results of a simple audit we carried out showed that the basic principles of the WHO method are not being implemented. There is a need to combine education and skills used for the management of pain and symptoms within the main healthcare system.

Using WHO guidelines to improve opioid availability, we aim to instigate a national policy for cancer pain and palliative care. This involves translating the written guidelines on the WHO method of pain relief into Greek and organising educational sessions aimed primarily at the main cancer care departments.

General wards and schools of nursing will be targeted, as well as the private sector, which, because of the lack of government inpatient facilities, cares for many cancer patients outside the capital. At present, the community staff are trained by PASYKAF which also provides educational opportunities for all health professionals in Cyprus.

### Palliative Care Awareness Group

In 1997, PASYKAF established a Palliative Care Awareness Group to focus on improving palliative care in Cyprus. This group comprises five nursing sisters working in the homecare setting, two oncologists with part-time involvement in the home-care service, two anaesthetists particularly involved in pain management, two pharmacists and a psychologist.

The first aim of the group, and, partly, the reason it started, was to overcome the lack of essential drugs for the control of cancer pain and other distressing symptoms. Until 1998, morphine was only available in a sustained release formulation of 30 mg and 60 mg. Also available were 10 mg/ml ampoules of morphine for injection. Later, in 1998, an immediate-release formulation of morphine became available but periodic shortages of availability inhibited its use in clinical practice. Clearly, it was necessary to improve the range of formulations to promote safe and effective management of cancer pain.

Our list of drugs was formulated from evidence-based information, such as that from the WHO (*Cancer Pain Relief* – 1996) and the EAPC Expert Working Group publication on the administration of morphine. Our own clinical experience highlighted the specific needs of the healthcare system in Cyprus, especially in the community, where patient care is supported only by the PASYKAF charity organisation.

To reach a consensus of agreement from medical oncologists, who would have to support our proposal, we organised a formal version of the rationale for the request of various formulations of analgesics, mainly morphine. We were disappointed by the lack of attendance by senior oncologists (there are no palliative care specialists in Cyprus) but appreciated the interest of approximately 35 health professionals from mixed cancer disciplines and departments such as the pharmaceutical services.

After discussion,we reduced the number of items requested on the list and selected the most appropriate to avoid over-importing drugs that may not be used because of the lack of knowledge and skills on how to use them.

The proposal was forwarded to the government department for consideration in April 1999, but so far no decision has been taken for the improvement in the availability of opioids in Cyprus. However, the request has not been rejected.

The next step is to deliver written guidelines for medical use in the management of cancer pain, which we hope will persuade the government department that we are serious about improving pain management in Cyprus.

## Societat Catalano-Balear de Cures Paliatives (Catalonian-Balear Palliative Care Society) (SCBCP)

*Josep Planas i Domingo, President*

Each academic year, the SCBCP holds about seven or eight monthly meetings to discuss a variety of subjects. At the end of each year we usually hold a one-day workshop to discuss a special subject in depth.

These activities are carried out under the auspices of the Catalonian-Balear Academy of Medical Sciences, which covers all medical specialities in Catalonia and the Balearic Islands.

In 1998–99, the SCBCP edited a book entitled *Recommendations on social work in palliative care*, the second in a series edited by the SCBCP.

Apart from these activities, in May 1999 we held the 3rd Congress of the SCBCP in Reus (Tarragona, Spain) with great success. It was attended by 300 people and more than 100 presentations were made.

## Sociedad Española de Cuidados Paliativos (The Spanish Society of Palliative Care) (SECPAL)

*Marcos Gómez Sancho, President*

In the first 15 years of palliative medicine in Spain, an important role has been played by the Spanish Society of Palliative Care (SECPAL), founded in January 1992. Thanks to the tireless efforts of its members it has spread the philosophy of palliative care through courses, symposia and conferences.

The SCBCP now has over 600 members from various professions and specialities. Since the founding of the Society, we have:

- Organised two national congresses (1995, 1998), with more than 1,000 professionals at each
- Sponsored several congresses and scientific meetings in different regions throughout Spain
- Produced a quarterly multidisciplinary journal, *Medicina Paliativa*, the society's official publication. Edited by Josep Porta, it was the first periodical on palliative care to be published in Spanish
- Distributed SECPAL's *Recommendations for Palliative Care* to more than 20,000 healthcare professionals
- Published the SECPAL *Directory of Palliative Care Programmes* (1997, 1998). The most recent directory lists over 1,200 professionals involved in offering care to terminal-stage patients in Spain
- Held a joint pilot scheme with the WHO and the Spanish Pain Society entitled *Towards a painless hospital* in 11 Spanish hospitals
- Contributed to the development of new rules for prescribing narcotics, applied in 1994 through meetings with the Ministry of Health
- Incorporated many regional organisations into its structure and remained active within the EAPC, in which it is a collective member. Internationally, it has taken part in many research, teaching and legislative commissions.

SECPAL has announced the following projects for the year 2000:

- Launching a revised *Medicina Paliativa*, possibly increasing circulation to Latin America

- Continuing work on training standards and programme organisation. Basic recommendations will be published for the healthcare authorities, advising on training and organisation of teams
- Extending the campaign *Towards a painless hospital* to basic health teams and hospitals in all Spanish regions, and evaluating and publishing the final results.

The society's main objective is to maintain its multidisciplinary structure and contacts with all types of institutions, societies and organisations involved in caring for terminally ill patients and their families.

## FORTHCOMING CONFERENCES

### 7TH CONGRESS OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE, PALERMO, ITALY

It is a great pleasure to host the 7th Congress of the European Association for Palliative Care in Palermo, from 1–5 April 2001. The EAPC will continue its tradition of ensuring a strong scientific programme which will challenge, inform and update all aspects of palliative care.

We firmly believe that exchanging information between professionals in any field is the most productive and effective way of educating ourselves and others. Much care has been taken to invite speakers from all areas of palliative care to share their experience and knowledge in an international environment.

Sessions will cover various levels of interest, including teaching and controversial topics. Most sessions will be available in English, French and Italian.

The venue for the congress is the Politeama theatre, in the heart of Palermo. The location is one of the most beautiful ancient squares of Europe, containing many attractions such as theatres, restaurants, churches, shops and museums. A diverse social programme will be offered, with special surprises. We will try to guarantee a fruitful congress covering many disciplines and diverse languages and cultures.

*Sebastiano Mercadante, Chairman of the Scientific Committee; Giorgio Trizzino, Chairman of the Organising Committee*

### 1ST INTERNATIONAL GERIATRIC PALLIATIVE CARE CONGRESS, NEW YORK, USA

Together with Beth Israel Medical Center, New York and our sister company, Events International Meeting Planners we are planning the 1st International Geriatric Palliative Care Congress to be held at the Roosevelt Hotel in New York from 11–14 October 2000.

**Invitation**

We are pleased to invite you attend this Congress, which will update the principles of palliative care as they apply to geriatric practice. Topics to be discussed include: the role of the hospice in the care of the dying, treatment of pain and other symptoms, ethical issues, evidence-based medicine, and the role of palliative care in long-term facilities.

The programme of plenary sessions, lectures, panel discussions and breakout sessions is structured to provide an overview of palliative care and how it relates to healthcare in general. International initiatives, psychiatric syndromes, the management of pain and other symptoms, legal and ethical issues, and evidence-based medicine will all be examined. Individual sessions cover congestive heart failure, chronic obstructive pulmonary disease, the frail elderly, caregivers, and psychosocial concerns. Medical directors of long-term care facilities are invited to an optional half-day core curriculum in palliative care.

An interdisciplinary approach will integrate the clinical, educational, and research aspects of geriatrics and palliative care. We hope that many of our members will join us and the prestigious international faculty for this exciting meeting.

*Russell K Portenoy, David I Wollner, USA*

Visit the EAPC website: **www.eapcnet.org**
Palermo website: **www.kenes.com/eapc**

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