# eons newsletter

The Quarterly Newsletter of the European Oncology Nursing Society

Fall 2007

## Contents:

**Editor in Chief:**
Jan Foubert, RN, MSc

**Editorial Board:**
Carol Krcmar, RN, MN
Emile Maassen, RN, CRN
Cath Miller, MA, RGN Dip Hsm

The goal of the EONS Newsletter is to inform nurses about EONS and its activities and to provide a forum for cancer nurses throughout Europe to network. The information published in the EONS Newsletter is intended to inspire nurses to improve the care of the cancer patient through improved knowledge.

All correspondence should be addressed to the Editor-in-Chief at:
eons@village.uunet.be

**EONS Secretariat:**
Rudi BrikÈ
Avenue E Mounier 83/4
B-1200 Brussels, Belgium
Tel: + 32 (2) 779 9923
Fax: 32 (2) 779 9937
E-mail: eons@village.uunet.be
Web site:
www.cancereurope.org/EONS.html

EONS acknowledges Amgen, Astra Zeneca, Merck, MSD, Munidpharma, Novartis, Nutricia, Roche, Sanofi Aventis and Topotarget for their continued support of the Society as Sustaining Members.

Print run: 4650 copies
Electronic version accessible to 24000 EONS members

**Printed by:**
Drukkerij Trioprint Nijmegen Bv
The Netherlands



# Our colleagues from FECS

*Mary Rice, FECS Communications*

Michel Ballieu, Chief Executive Officer of the Federation of European Cancer Societies since last November, enjoys a challenge. From his first days at FECS when he understood he had to temporarily give up his private life to sort out the crisis situation he had inherited, he has been motivated by the need to set things right for the member societies. "With previous experience in the not-for-profit sector, I knew that federations were the most difficult organisations to manage", he says. "One of the problems is that often they are run by their management and staff in a top-down manner, whereas the only way in which they can be successful is if they are truly responsive to their members' needs. I was determined to institute this bottom-up approach at FECS as soon as I could."

After 10 years at association management company MCI, as Executive Director for several associations, Ballieu was ready for a new challenge. But even so, his first day at FECS was a bit of a surprise. "When I arrived I realised the extent of the staffing problem. I had thought that there were at least 7 or 8 staff members remaining from a team of twelve, but I found only five who were still there. And it got worse - one person had only been there two months, one was only committed to the office for 20% of her time, and one was pregnant and about to go on maternity leave. My first reaction was: "How could I have made such a big mistake and given up a good job for this mess?" he says. But after the initial shock he realised the importance of the challenge and started looking for staff as a matter of urgency. He stopped his daily early morning gym visits in order to be in the office at 6.30 am and was rarely home before 9 pm. For the first two months he used his existing network of contacts to try to locate good candidates for the posts which it was essential to fill if FECS were to continue to be able to support member societies in the organisation of their conferences.

"I was very fortunate to have found so many good people so quickly", he says. So quickly, indeed, that none of the planned conferences have had to be contracted out, which was the solution that had been originally suggested. In this he was also helped by the staff members who had stayed. "The 'old-timers' have helped enormously by making their repository of knowledge available to new recruits, and aiding them through the transition period", he says. "And we, the "imported new-comers", also pay tribute to the former team who built the great success of our congresses and conferences."

"Today I am proud of our very well balanced team of 15, 5 old-timers and 10 new members, 9 women and 6 men, 5 Belgian Flemish, 5 Belgian French, 5 expats, all in place and operating well. Together we represent 5 nationalities and speak 7 languages".

So with the new team in place, what happens next? Clearly there were major problems at FECS which led both to the haemorrhage of staff, and to ESMO's decision to leave the federation. Although it has been extremely difficult to handle, and a big shock to many, in the longer-term good will come out of this situation, says Ballieu. "ESMO leaving was the catalyst for change. A new structure has been developed that will enable maximum consultation between member societies, and encourage new members among those societies which qualify by being pan-European, with sufficiently large membership to be representative of their specialisation, and with a major focus on oncology. Founder members


must feel that they have the right to guide and develop this evolutionary expansion. I have had the impression that in the past they have not always felt sufficiently involved and that this has been in part a reason for some of the recent troubles.

FECS will re-launch next September in Barcelona with a new name – the European CanCer Organisation (acronym ECCO) – and a more patient-focused mission. "In five years time I would like to see that the 'faculty' has learnt to work in harmony and that patients have confidence in it", says Ballieu. "If this is the case, it will be much easier to encourage funding organisations to increase their investment in cancer research, and to persuade policymakers of the real needs and aspirations of patients and those who care for them."

# Letter from the editor.

## Brussels, August 2007

-Welcome to the EONS newsletter Fall 2007 and when you read this newsletter during the 14th ECCO conference, then welcome to Barcelona and I hope you will enjoy the ECCO conference. This issue is also translated into Spanish, the language of the hosting country of the conference. I would like to thank our Spanish colleagues for all the effort and the collaboration in the development of this issue.
This conference is again organised by FECS (Federation of European Cancer Societies) but FECS will re-launch in Barcelona with a new name – the European CanCer Organisation (acronym ECCO) – with a more patient-focused mission. More about our colleagues from FECS can be found in this newsletter.

In Europe we live in a multi-cultural society and this has an impact on the delivery of health care. When adapting the health care services to the needs of multicultural populations, governments of member states should base their policies on values propounded by the Council of Europe – human rights and patient's rights, human dignity, social cohesion, democracy, equity, solidarity, equal gender opportunity, participation, freedom of choice – balanced by the obligation to help individuals look after their own health. Member states should apply a systematic approach to issues related to responding to cultural diversity. Guidelines and standards for the provision of good services in multicultural populations should be developed. Developing coherent and comprehensive policies and strategies addressing health care needs in multicultural societies, including prevention, should include:

- protecting human dignity and preventing social exclusion and discrimination;
- promoting delivery of high quality, linguistically appropriate, culturally sensitive, equitable and appropriate health care services;
- promoting changes in the conduct of health authorities at the national and local level and of health and social professionals to adapt their response to the health needs of multicultural populations;
- developing cultural competence in health care providers (meant as the ability to provide effective health care services taking into consideration the individual's gender, sexual orientation, disability, age and religious, spiritual and cultural beliefs).

Health disparities in multicultural societies may have different causes, including external ones. These include cultural and socio-economic factors, migrant status and discrimination. Member states should pay attention to those factors in the appropriate policy settings as part of a comprehensive, coherent overall policy approach that focuses on eliminating the external causes of disparities in the health field. (Recommendation Rec (2006)18 of the Committee of Ministers to member states on health services in a multicultural society) In developed and developing countries, there are basic differences not only in resources available for patients suffering from cancer but also in the meaning they attach to the illness experience. The expression of needs and how they are met in different cultural contexts may provide a clearer assessment and insight for initiatives of how cancer care should be perceived and administered. More about this and how this affects the family can be found in the article of Professor Lea Baider from Israel. Also in this issue an article "Cancer Care in Spain: a Patient's Perspective "and as the writer tells us "In one sentence, my experience of the Spanish health system and its hospitals has been excellent!".

Not only patients are moving from one country to an other country also nurses are mobile and are needed across Europe.
Today's global nursing shortage is having an adverse impact on health systems around the world. A major initiative by the International Council of Nurses (ICN) yielded important information regarding the shortage and solutions to it. These are organized into five priority areas: policy intervention; macroeconomics and health sector funding; workforce planning and policy, including regulation; positive practice environments; and retention and recruitment (includes migration); and nursing leadership.
In Europe, the Standing Committee of Nurses of the EU (PCN) confirms that nearly every country within the EU is reporting severe shortages of nurses. Qualified nurses are leaving the profession and the number of new entrants to nursing courses is falling. Demographically, the workforce is ageing, which implies that a further crisis is just around the corner.
When nurses choose to migrate between countries and health systems, it has significant implications for both the importing and exporting country. Without migration, the shortage of nurses might be expected to push up the salaries of nurses; with it, nurses' salaries are unlikely to improve. Recruitment of nurses from countries with lower standards of living is likely to depress salaries within importing countries.
Predicted shortages and recruitment targets for nurses in developed countries threaten to deplete nurse supply and undermine global health initiatives in developing countries. A twofold approach is required, involving greater diligence by developing countries in creating a largely sustainable domestic nurse workforce and their greater investment through international aid in building nursing education capacity in the less developed countries that supply them with nurses

Maria Mercadè Virgili and Roger Santamaria Pocurull describe their experience in the article « Nurse mobility in Europe: an adventure that changed into a series of projects and goals". Sometimes nurses are leaving their country to undertake training and The Experience of Undertaking Doctoral Study in the UK is described in the article from Maria Arantzamendi.

The winner of the best Titan dissemination award 2006 is Hilary Noonan from Ireland, you can read the abstract Improving the Management of Febrile Neutropenia in Paediatric Patients with Cancer: Experience from a shared Care System in Ireland, in this issue. Congratulations to Hilary for this fantastic project that hopefully will serve as an example for all our members who have recently finished a TITAN course and who have to make a dissemination plan.

For those who have an interest on what is going one across the ocean there is the article "Highlights from the Oncology Nursing Society 32nd Annual Congress "Viva Las Vegas" written by Jane Bryce.

Furthermore you can find in this newsletter some interesting articles on the following topics:

- The NCCN guideline for distress management: A case for making distress the sixth vital sign.
- Reducing the misery of oral mucositis.
- Anthracycline Extravasations in Clinical Practice

Finally you can also read an interview with the current president of EONS, Yvonne Wengström reflects on her term as president. We wish Yvonne all the best and a good life as immediate past-president and we welcome our new president Sarah Faithfull and wish her a dynamic and happy life as the new EONS president.

Jan Foubert, Editor in chief.

# Welcome message to the city of Barcelona

*Paz Fernández-Ortega RN, PhD©*

If you decide to attend the ECCO Conference, you will see a lot of people talking in the halls. You may even see some hugging on the first day. You will begin to think "everyone knows each other and I don't know anyone." We promise you this will be just for a short time and soon you will have the opportunity to meet new colleagues, friends, as well as wonderful experiences, exchanging valuable ideas on nursing and professional matters.

On the occasion of the ECCO Conference in Barcelona and in liaison with the Spanish Oncology Nursing Society, I would like to offer an enthusiastic welcome to the dedicated community of cancer nurses who are attending this conference.

For the first time we have organized the European cancer conference in a Mediterranean context and we are very pleased to be hosting this nursing event. The world knows Barcelona and its success as city joining tradition and modern and above all how this wonderful city and its people will make you feel welcome to ensure you enjoy the delights of this unique city and coast.

Bringing together experience of nursing with other health care professionals ensures we are all working together to achieve the best conference on behalf of cancer care. We can wait no longer.

I would like to introduce you to our Oncology Nursing Spanish Society

SOCIEDAD ESPAÑOLA DE ENFERMERÍA ONCOLÓGICA

The Spanish Oncology Nursing Society, Sociedad Española de Enfermería Oncológica (SEEO) was registered as a Scientific Organization in 1985 in the city of Granada on March 30th, presenting to the Ministry its regulations, by-laws and Board members composition. First congress took place in Pamplona in April 1986, under "Nursing Care for Cancer Patient ".
We are preparing now, the 11th NATIONAL CONGRESS, that will be in Granada on the 30th and 31st May, and the 1st and 2nd June 2007.

This year Granada is one of the candidates to become one of the New Wonders of the World. To all those who have visited, please consider voting.
Our society has 350 members, thus being one of the largest Spanish nursing societies. We are members of both the EONS European Oncology Nursing Society and the International Society of Nurses in Cancer Care (ISNCC). We are also part of the National Federation of Nurses Societies (FESCE) and we have an excellent relationship with some other societies, such as Brazil, Panama, Chile, Uruguay, Colombia, USA and Portugal. In the recent past we were represented at the "Europe Against Cancer Spanish Committee".
During the year 2001 and 2002 the Society was integrated in the Advanced Clinical Practice Plan & Recognition for Cancer Nursing as an independent speciality, constituted by national experts. Despite our efforts, to date we have not yet achieved our goal of recognising oncology as a nursing specialty. We continue to collaborate in designing the training plans and specific requirements of oncology nursing.

**Board members**
The SEEO is governed by a Board constituted by a President and a Vice-president, a treasurer, a general secretary and ten speakers from different geographical areas of the country, bringing different expertise such as Medical Oncology, Radiotherapy, Onco-

Haematology, Day Hospital, Home care and Research and University.

**SEEO's mission statements from its statute state:**
To bring together professionals who take care of patients with cancer in different areas and assistance levels, and to support their efforts at all levels, whether local, regional, national, European or international.

- To work on the population health's education for cancer prevention and the adoption of a healthy lifestyle.
- To promote communication between professionals and to unify criteria for professional performance.
- To provide recent up-dated knowledge to its members.
- To improve the quality of care and to guarantee continuing education
- To identify a body of knowledge in oncology nursing
- To define the profile of oncology nursing
- To foster research in our own issues

**Scientific activities**
The Sociedad Española de Enfermería Oncológica (SEEO) has undertaken several scientific activities during its existence.

Many workshops on monographic topics, congresses, courses and forums of discussion, always have followed a common guideline, which is to provide elements for the reflection and revision of nurses own practice and to continue to build among its own professionals the voice of the cancer nurse. The revision of these texts constitutes an exponent of the continued progression. Debating the themes as we have proposed, has been a true challenge, but is what determines the adaptation of our proposals to meet the demands that we perceive in the population in relation to cancer and to build a specialized oncology nurse service to meet this demand.

**Benefits for members**
During our Oncology Nursing Spanish Society existence, we have celebrated different educational events such Symposiums:

- "Care of patients receiving Radiotherapy" or "Quality of life in the cancer process", Meetings in Cancer Nursing; Meetings and Days as Paediatric oncology and radiotherapy nursing care; Nursing Days in onco-haematology or day hospital; National Meeting and Days of nursing care in bone marrow transplantation; Wokshops in the management of oncology units; education of patients with cancer; and oncology nursing competencies;
- Courses: Methodology of the research applied to the care in oncology nursing. Fatigue in the patient with cancer; Semi-presented Course / Workshop: Qualitative research methodology applied to cancer nursing.
- Other benefits include the opportunity to participate in special interest working groups and taking advantage of discounted conferences registration fees.

**Under EONS Umbrella**
SEEO is represented at the European Society by a Board member in the Advisory Council meeting. Spanish Society has participated in several of the EONS activities and initiatives such "Action on Fatigue", "Learning to Live with Cancer", NICCI (Educational Initiative in Colorectal Cancer), NOEP in Cancer Nutrition, TITAN and next month of June will start the TARGET and, we hope to participate in many others in future!!.

**Publications**
SEEO has an official scientific journal, including the following sections in it:

- Leading article
- Original article
- Literature Review
- Onco-Internet
- Courses and congresses
- News from Europe and International.
- Legislation

It is issued four times, once every season of the year. Winter, Spring, Summer & Fall

Moreover, the SEEO offers to oncology nurses a Research Grant, since we believe cancer nursing research plays an important role in the quality and evolution of the care and the professional development of nurses. Both have a direct effect on health in relation to cancer nursing practice and in the decision-making in organizations at operational and strategic levels.

**What about the future?**
Recognising how complex, and changing the future could be for cancer nurses and patients in Spain, our challenges are to continue our effort to enhance cancer nursing care, clinical practice and education for nurses and to achieve the professional recognition and speciality in Cancer Nursing in partnership with Europe!

We invite you all, as European colleagues to visit our webpage HYPERLINK "http://www.seeo.org" www.seeo.org which receives around 40.000 visits per year.



# Anthracycline Extravasations

## in Clinical Practice

*Helen Roe, Consultant Cancer Nurse / Lead Chemotherapy Nurse, North Cumbria Acute Hospitals NHS Trust, United Kingdom.*

**Introduction**

As Maike de Wit discussed in the first article of this series (please see the EONS Summer 2007 Newsletter) the number of patients receiving chemotherapy who sustain an anthracycline extravasation is very low and some professionals will not have seen one in their professional career. When considering the number of patients who experience an anthracycline extravasation, we need to keep these numbers in context by also recognising the number of anthracycline containing regimes administered within clinical practice. It is therefore vital that professionals who administer chemotherapy are aware of the signs and management of an extravasation (1).

This article will present two detailed case studies and one recollection as a way of demonstrating different management options previously used in clinical practice for the management of anthracycline extravasations. Unfortunately, there is not much evidence to support these traditional options as the treatment options described are largely anecdotal and based on small numbers of patients (2-4). For the purpose of this article, patient details have been changed to protect their privacy; both patients consented to their experiences being shared in this format to help educate other professionals caring for patients who have sustained an anthracycline extravasation.

**Conservative Treatment with Dimethyl Sulphoxide (DMSO): Case 1**

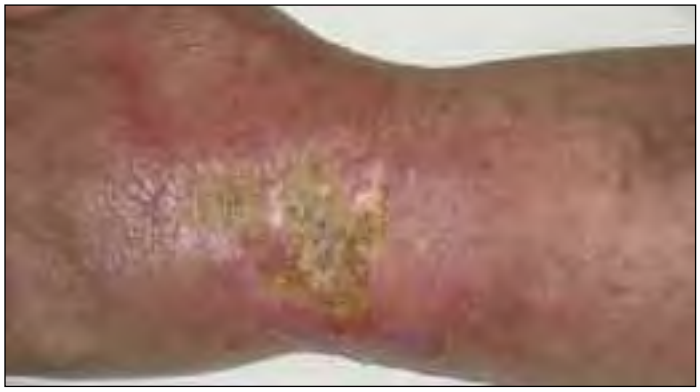
Mrs Smith was a 63 year old lady, who had a mastectomy and axillary clearance for a grade 3 breast tumour. Following discussion with the clinical oncologist she was advised to receive adjuvant FEC100 chemotherapy (5-Fluorouracil, Epirubicin and Cyclophosphamide).

I met Mrs Smith and her husband when she attended the nadir clinic, approximately ten days following the administration of the third cycle of chemotherapy. During the consultation she commented on the administration of the second cycle of chemotherapy; how there had been a problem inserting the cannula and that she had fainted during her treatment. She also stated that during the treatment some of the red chemotherapy (Epirubicin) had been accidentally spilt on the back of her hand. A key point to note at this time was that Mr Smith was a photographer and had taken photographs of his wife's hand since her last cycle of chemotherapy and they had pages of notes, which was very helpful in piecing the events together.

These notes described how the day after receiving her second cycle of chemotherapy the patient noticed that her hand was red, swollen and rather painful at the site where the chemotherapy had been administered. She was advised by a nurse from the treatment unit to 'keep an eye on the area' and contact them again if she noticed any change. The nursing documentation relating to Mrs. Smiths second cycle of treatment stated that there had been two cannulation attempts and that a small vein had been used to administer the chemotherapy. It also stated that she had fainted during the administration but soon recovered and the chemotherapy continued to be administered as prescribed.

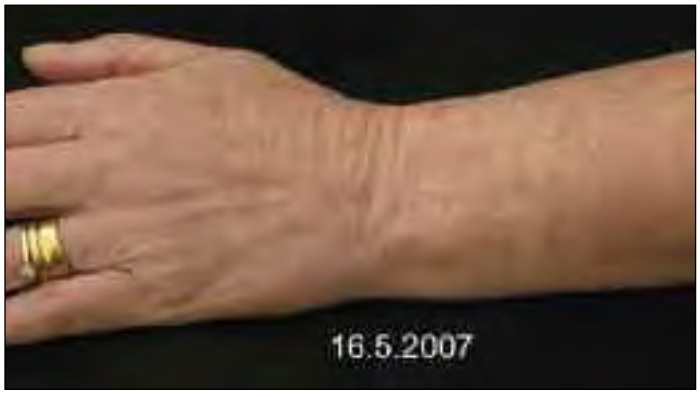
A few days later, Mrs. Smiths' hand was no better and she contacted her general practitioner who felt she may have cellulitis and prescribed her a course of antibiotics. She was subsequently routinely assessed in the nadir clinic following her second cycle of chemotherapy. A medical review supported the general practitioners diagnosis of cellulitis, with the area where the cannula had been sited being described as having 'marked swelling and blistering'. No changes were ordered in her management and Mrs. Smith was scheduled for her third cycle of chemotherapy in accordance with the protocol.

After observing the area, reading their account of events, reviewing the nursing documentation and speaking to their general practitioner, I contacted the patient's oncologist to discuss my suspicions that she had suffered an extravasation relating to the cannulation or a possible chemotherapy spillage. I obtained some digital images (photograph 1), emailed them immediately to the oncologist, and arranged for the patient to be assessed by the oncologist. Following discussion with 'extravasation.org' the decision was made to apply Dimethyl Sulphoxide (DMSO). The rational for its use and possible outcomes were discussed with Mrs. Smith and her husband. Despite DMSO being listed in many management guidelines as an antidote (6) it does not have authorisation for use in the management of anthracycline extravasation (7, 8).



*Photograph 1: Hand of Mrs Smith – Nadir clinic visit (following cycle 3)*

Mrs. Smith continued with her chemotherapy and received regular reviews and the DMSO treatment continued for approximately six months until the area was fully healed. Mrs. Smith was able to maintain full movement of the affected hand (photograph 2), although the success of DMSO could be questioned due to the period of time treatment was necessary.




*Photograph 2: Hand of Mrs Smith - 21/2 years after extravasation*

**Conservative Treatment with Hyaluronidase, 'Flush out' and DMSO: Case 2**

Mrs. Jones was a 47 year old who had a mastectomy and axillary sampling for a grade 3 breast tumour. Following discussion with the clinical oncologist, she was advised to receive adjuvant chemotherapy (the same treatment protocol as described in Case 1).

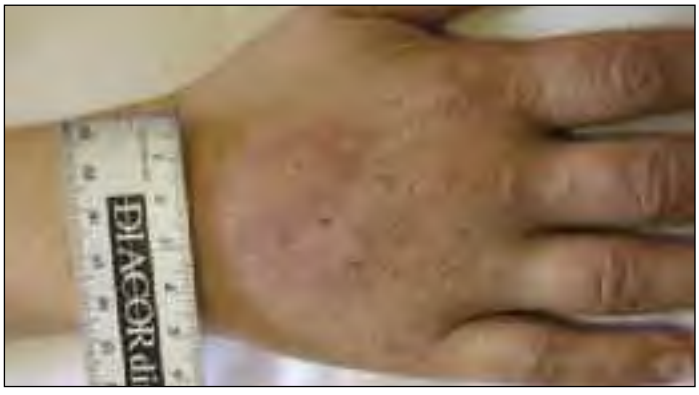
Mrs. Jones had received her first three cycles of chemotherapy with no noted ill effects. The day after the administration of her fourth cycle of chemotherapy she telephoned the department as she was concerned about the hand were the chemotherapy had been administered as it was swollen and painful and she could not move her fingers due to the swelling.

She explained, using her own words, what had happened the previous day, how the nurse had experienced difficulties accessing a vein and after the chemotherapy was completed the area where the cannula had been was red. She stated that the doctor had examined her hand and said he felt it was bruising around the cannula site and gave her hydrocortisone to apply to the area. She was instructed to contact the oncology clinic if the area did not improve. The nursing notes showed where the cannula had been sited and described the cannulation as being difficult, but indicated that the chemotherapy had been administered without any adverse effects. The only point to note was the redness when the cannula had been removed, which the doctor had also observed.

As Mrs. Jones did not live near the hospital it was agreed that her husband would email me some photographs of her hand to enable me to review them and discuss her management with the oncologist. This we did and I arranged for her to urgently attend the hospital to be examined as I felt the photographs demonstrated a possible extravasation. I also contacted the regional plastic surgery unit for advice as our policy had now changed and stated that all possible anthracycline extravasations should be reviewed by a plastic surgeon in regard to possible 'flush out'. They instructed us to first examine Mrs. Jones and if it was thought to be an extravasation,

Hyaluronidase should be injected subcutaneously (3, 9) and then she could be transferred to their care. The patient was reviewed by their on-call team and they performed 'flush out' under local anaesthetic (10) and monitored her progress over the next few months.

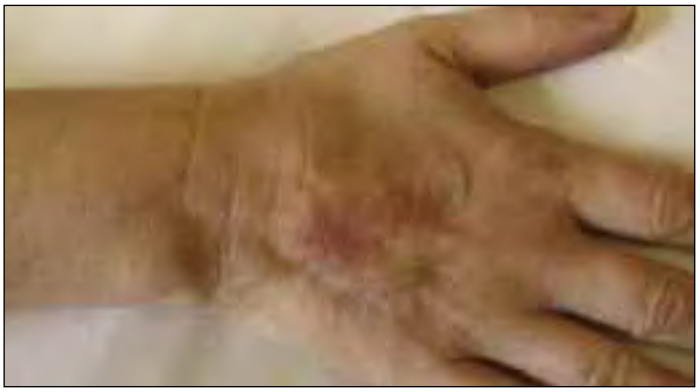
Mrs. Jones was examined in our oncology clinic the week prior to her next planned cycle of chemotherapy. However, at this point the flushed area appeared very red, slightly swollen and painful (photograph 3). The oncologist prescribed a course of antibiotics and decided to commence DMSO and topical hydrocortisone treatment to the 'flushed area' to enable her to continue with her planned chemotherapy.



*Photograph 3: Hand of Mrs Jones – following 'flush out' under local anaesthetic*

Mrs. Jones completed the rest of her chemotherapy, but as with Mrs Smith, the chemotherapy was administered in the arm on the side of her surgery. She continued with the DMSO treatment and the 'flushed' area remained red, although it appeared a more 'normal' skin colour than it had been, the swelling subsided, and the skin temperature returned to normal.

Two years after the event (photograph 4) Mrs. Jones commented that her hand was still painful and the skin felt very tight and did restrict some of her normal daily tasks. It is therefore questionable as to the effectiveness of the 'flush out' technique and the application of DMSO in this case.



*Photograph 4: Hand of Mrs Jones - 2 years after extravasation*

**Surgical Intervention - Debridement and Skin graft**

Despite working in various cancer settings in England for approximately twenty years, I have only known of one patient who required debridement and skin graft after sustaining an anthracycline extravasation. This is, however, the standard treatment for an anthracycline extravasation and is used in 25%–80% of patients (11-16). However, there are no controlled studies to support this form of intervention, especially when dealing with small volume extravasations. It does reinforce the need for patients to be reviewed by a plastic surgeon experienced in the management of anthracycline extravasations to determine if the patient may require treatment with a systemic antidote such as Savene, or 'flush out' or debridement and skin graft (3).

If a patient does not respond to conservative treatment or experiences persistent swelling, pain and erythema, even if there are no signs of ulceration, they require an urgent consultation with a plastic surgeon (3, 17). If blistering, ulceration and pain are present there is a clear requirement for surgical intervention to remove any residual anthracycline from the tissue (18). The primary aim of treatment is to preserve the function of the area involved and alleviate pain. Surgical intervention would consist of removal of the area of extravasation and surrounding red/painful area to ensure all residual anthracycline is removed (15) (photograph 5).

*Photograph 5: to demonstrate the process of debridement in preparation for skin grafting (The photo is by courtesy of R. Bodenmüller-Kroll)*

One patient in my clinical experience who underwent debridement and skin graft suffered a delay in receiving his scheduled chemotherapy regime due to an infection which followed the surgical intervention. This patient later found it very hard to accept the disfiguration of his body in relation to the donor and skin graft site.

*Photograph 6: To demonstrate possible disfiguration following skin graft (The photo is by courtesy of R. Bodenmüller-Kroll)*

The most appropriate management for anthracycline extravasation was unclear (11) until the introduction of SaveneTM, the only antidote which is proven and has been approved for the management of an anthracycline extravasation. This agent has the potential to improve the outcome of patients who experience an extravasation, especially as the supportive evidence for SaveneTM is based on greater numbers of patients and obtained from two prospective clinical studies of biopsy proven cases (19). It should be noted that the effect of SaveneTM is optimal if administered as soon as possible and within 6 hours of the extravasation incident.

**References**


1. Webster J.S. Immediate complications of cytotoxic therapy. In Polovich M., White J. & Kelleher L, (Eds): Chemotherapy and biotherapy guidelines and recommendations for practice, 2nd edition. Pittsburgh, 2006, Oncology Nursing Society. Chapter VI.

2. Wickham R. et al. Vesicant extravasation part II: Evidence-based management and continuing controversies. Oncology Nursing Forum. 33: 6: 1143-1150, 2006.

3. Ener R.A. et al. Extravasation of systemic hemato-oncological therapies. Annals of Oncology. 15: 858-892, 2004.

4. Kretzchmar A et al. Extravasation of Oxaliplatin. Journal of Clinical Oncology. 21: 4068-4069, 2003.

5. Dorr R.T. Antidotes to vesicant chemotherapy extravasations. Blood Reviews. 4: 41-60, 1990.

6. National Extravasation Information Service. Treating extravasation injuries. http://www.extravasation.org.uk/treating.htm#antidote – accessed 05/07.

7. Alley et al. Cutaneous toxicities of cancer therapy. Current Opinions in Oncology. 14: 212-216, 2002.

8. NHS Pharmaceutical Quality Assurance Committee. Guidelines for the purchase and supply of unlicensed medicinal products – notes for prescribers and pharmacists'. 3rd edition. Olin B.R. (Ed) (1998) Drug Facts and Comparisons. St. Louis: Facts and Comparisons, Inc; 740-740a, 2004.

9. Allwood M. et al. The Cytotoxic Handbook. Oxford, 5th edition. 2003, Radcliffe Publishing.

10. Murphy P.M. & Gault D.T. Treatment of extravasation injury. The National Extravasation Information Service. http://www.extravasation.org.uk/Lett.htm - accessed 05/07.

11. Langstein H.N. et al. Retrospective study of the management of chemotherapeutic extravasation injury. Annals of Plastic Surgery. 49: 369-374, 2002.

12. Preuss P, Partoft S. Cytostatic extravasations. Annals of Plastic Surgery. 19: 4: 323-327, 1987. 10

13. Loth T.S. & Eversmann W.W. Treatment methods for extravasations of chemotherapeutic agents: a comparative study. J Hand Surg, 11: 3: 388-396, 1986.

14. Pitkänen J. et al. Adriamycin extravasation: Surgical treatment and possible prevention of skin and soft-tissue injuries. Journal of Surgical Oncology, 23: 259-262, 1983.

15. Larson D.L. What is the appropriate treatment of tissue extravasation by antitumor agents? Plast Reconstr Surg. 75: 397-405, 1985.

16. Reilly J.J. et al. Clinical course and management of accidental adriamycin extravasation. Cancer. 40: 2053-2056, 1977.

17. Rudolph R. & Larson D.L. Etiology and treatment of chemotherapeutic agent extravasation injuries: A review. Journal of Clinical Oncology. 5: 1116-1126, 1987.

18. Bozkurt A.K. et al. Intrathoracic extravasation of antineoplasmic agents: Case report and systemic review. American Journal of Clinical Oncology. 26: 121-123, 2003.

19. Mouridsen H.T. et al. Treatment of anthracycline extravasation with Savene (dexrazoxane): results from two prospective clinical multicentre studies. Annals of Oncology. 18: 3: 546-550, 2007.


# FECS – the facts

- FECS - the Federation of European Cancer Societies (to be re-launched in September 2007 as **the European CanCer Organisation – ECCO**) was set up in 1994 to represent all disciplines involved in cancer care, research and treatment.

- Today gathering and representing some 25.000 professionals in oncology

- ECCO will uphold the right of all European cancer patients to the best possible treatment and care, and to promote interaction between all disciplines involved in cancer at European level. It aims to provide a platform for progressive thinking in cancer policy, training, and education.

- Structure:
  - An Advisory Council currently composed of 17 members (including EONS)
  - A Membership currently composed of 12 members (including EONS)
  - A Board of Directors (16 individuals), The Board will seek help and advice from this Council
  - An Executive Committee (6 officers, who will report to the Board)
  - An office located in Brussels and managed by the CEO (Michel Ballieu)
- 

For further information on the new organisation, please visit www.tobeconfirmed.org as of September 24, 2005

**EONS Election Results**
The EONS Nominating Committee is pleased to inform the membership that EONS has a new Executive Board and a President elect, this as a result of the voting which took place in May 2007. The following individuals were elected as Board Members for the period of September 2007 to October 2009:

- Rolf Baumer, Germany
- Françoise Charnay Sonnek, France
- Daniel Kelly, UK
- Kay Leonard, Ireland
- Anita Margulies, Switzerland
- Ulrika Östlund, Sweden

**Mrs. Sultan Kav** has been elected as President-elect for the same time period.

On behalf of the Executive Board, the Advisory Council, and the general membership of the Society, we wish the newly elected Board Members all the best in carrying out their responsibilities. We would like to thank the out-going Board Members for their valuable contribution to the Society and wish them all the best in their future endeavours.

The newly elected EONS officers will be installed into office at the general meeting during the upcoming ECCO conference in Barcelona

**Meeting of the EONS Advisory Council: November 2007**
A meeting of the Advisory Council will take place on Saturday, November 17th from 10:00 – 17:00 in Brussels, Belgium.

Preliminary information on the meeting has been sent to members of the Advisory Council. More detailed information on the venue as well as the agenda will be sent to participants in due time.

With the September 2004 Advisory Council meeting in mind, a precedent was set to open Advisory Council meetings to the EONS general membership. All members are herewith invited to attend the November meeting as observers. Travel and accommodation must be covered and arranged by individuals.

If you are interested in taking part in this meeting, please contact the Secretariat for more details: eons.secretariat@skynet.be or fax 0032 2 779 99 37.

Updated information on the meeting is available on the website: http://www.cancerworld.org/

**2007 World Congress on Gastrointestinal Cancer**
EONS participated in this conference, organized in collaboration with the European Society for Medical Oncology, in the special nurses' symposium. Speakers and topics presented were: How to talk with patients about their supportive care, Jan Foubert; How to deal with toxicities of targeted therapies - EGFR inhibitors, Liesbeth Lemmens; How to deal with toxicities of targeted therapies – VEGF inhibitors, Hilde Marsé; Is oral chemotherapy an option in treatment of CRC?, Paz Fernandez; and the Role of multidisciplinary approach, Mario Dicato. In a session on future issues, Jan Foubert presented an overview of the nurses' point of view.

Thanks to travel grants given by Amgen and Merck Serono, six nurses from Belgium, Lithuania, Bulgaria, Albania and Hungary were able to attend this meeting. We will report on this event in a future EONS newsletter and we hope that a nurses' symposium will be standard in future conferences.

Sharing solutions for cancer therapy management

Involve is a new initiative from sanofi-aventis for oncology nurses to share information about cancer therapy management. The main objective of this initiative is to involve and include oncology nurses in all prevention & treatment decision making thereby bringing together expert knowledge in a multi-disciplinary forum.
The inaugural initiative of Involve is the EONS accredited educational programme for oncology nurses, acknowledging 3 study hours towards continuing education, planned for the 23rd of September 2007 in Barcelona before the start of ECCO14.
The main goal of this programme is to provide oncology nurses with state-of-the-art education on the latest advances in the therapy of breast cancer and how these advances impact the therapy management of patients with breast cancer.

**New Board elected for Lithuanian Oncology Nursing Society**
The Lithuanian Oncology Nursing Society has also recently elected a new Board. The President is Mrs. Jurgita Gulbiniene and she will also act as the representative of the Lithuanian Oncology Nursing Society within the EONS Advisory Council.
On behalf of the EONS Board, we would like to welcome her to EONS and look forward to good collaboration with her society. We say goodbye to Mrs. Jolanta Toliusiene, the previous president and representative to EONS, and we thank her for her contribution and support to EONS.

**Accreditation Update**
The following courses have recently received EONS accreditation:

Universitätsklinikum Freiburg, Akademie für medizinische Berufe, Freiburg, Germany.
Weiterbildung „Pflege in der Onkologie", longer course. More information is available at: www.uniklinikfreiburg.de

Departement of Oncology Karolinska University Hospital, Stockholm, Sweden. Chemotherapy: Nursing care, administration and safety precautions. Short course, 3 days, offered four times per year.

**Training Programmes in Psycho-Oncology**
The International Psycho-oncology Society (IPOS) is pleased to announce the availability of two core programmes in psycho-oncology.
The programmes are, 'International, Multilingual Online Training Programme in Psycho-Oncology' and 'A Core Curriculum in Psychosocial Aspects of Cancer Care'. Both programmes are presented in English and translated to French, German, Hungarian, Italian, and Spanish. The translations have been modified to be culturally specific.
The programmes are offered on the website of the International Psycho-Oncology Society and on cancerworld.org, go to ESO, multimedia and training and you will have access to the modules.

## EONS' Sustained Partners










# Nurse mobility in Europe:

## an adventure that changed into a series of projects and goals

*Maria Mercadè Virgili and Roger Santamaria Pocurull, Valleiry (Francia)*

A fellow student of ours used to say that being a nurse is, 'the best way to travel at the moment' and he was quite right! Our own experience of nursing in Europe began as an adventure, and as time went by, the adventure changed into a series of projects and goals.

We graduated with a degree in nursing from the Nursing School of the Universidad Rovira i Virgili in Tarragona which we attended between 1999 and 2002. We were fortunate during the second year of our studies to receive a three-month Erasmus grant to visit the Univercità de Modena e Reggio Emilia in Italy. Thus, we felt the urge to travel with all of the implications that this involved, including a new culture, a new language and new people.

Thanks to the Erasmus grant, we had the chance to undertake some of our training at the Hospice Casa Madonna dell'Uliveto. This unusual place, with its own structure, philosophy and humanism impressed us and awoke our interest in palliative care, providing us with the chance to reflect upon the nature of nursing and what it should be. Up to that moment, we thought that care was mainly centred on the execution of clinical tasks, leaving the more complex needs of patients and their families in the background. Now, full of good experiences and with a taste for adventure, we went back to Spain to finish our studies, but had no idea that one year later we would be leaving again for a different destination.

We were not the only ones with a taste for adventure on this occasion, and together with four students from the same class, we decided to start a new professional adventure. There were many job offers abroad, but it did not take us long to make a decision to go to France. In fact, we signed our first open-ended contract of employment there scarcely realising the changes that would follow. We were compelled to leave Spain not because of the need to work, since we all had a job at that time, but because we wanted to experience, know and live in a country different to our own.

The quality of the contracts we signed was good in comparison to Spanish employment contracts. For instance, we were given an open-ended contract of 35 hours per week together with an installation premium amounting to 1,500 euros and an intensive month-long French language course during which time we were paid our normal nursing salary. They also provided a return trip plane ticket to Spain and arranged all of our accommodation paying the necessary security deposits. In return, we had simply to spend one year in the same institution.

At first we could only see the advantages of such a situation, but once in the city and at the work-place, those advantages are seen from a different perspective. The contract conditions remained the same, but they were not that important anymore. Certain difficulties appeared that we had not imagined prior to our arrival including the difficulties of daily life in a new culture with a new language that you have to learn in order to survive.

Another aspect we had not considered was the distance separating us from our country and our families. Our mood changed as months went by, and we felt an urgent need to meet our family and friends, to eat the typical dishes of our homeland - which do not taste the same in another country even though we were able to prepare them for ourselves in France. When that moment arrived, the thought of travelling 900 kilometres to be with your family does not seem important anymore as homesickness begins to creep in.

At first it was difficult to cope with the reluctance, rejection and comments of some of the people we met in France. We were told more than once that we were stealing the jobs of French people and others made fun of our accent when speaking French, making faces at us. This is a humiliating reaction; since they did not seem to appreciate the considerable efforts that we were making to communicate with them and do our jobs well.
According to our experience, and the hospitals in which we worked, the differences in nursing between France and Spain are not remarkable - in contrast to the provision of primary health care which is organised very differently in the two countries, but after a time, we all took jobs across the border in Switzerland, crossing the border every day to go to work thirty kilometres from our lodgings, although this is by no means unusual. The French region in which we live is very close to the border with the Swiss canton of Geneva region, so a great number of people cross the border every day to benefit from the better economic and working conditions in Switzerland.

Having worked now in both France and the Switzerland, we can say that there is a great deal of difference in the nursing cultures of the two countries (and indeed, our own). For us, the biggest and most important difference is the greater amount of time that nurses have to spend with patients and their families in Swiss hospitals. The main reason for this is the fact that the nurse–patient ratio is higher in Switzerland than in either France or Spain. For example, the average number of nurses per shift in Switzerland is between four and five (plus two nursing auxiliaries) for an average unit of sixteen patients and at night there are always two nurses on duty. In other institutions, such as residential homes for the elderly, with which we are familiar, there is one qualified nurse and as many as eight nursing auxiliaries to look after 29 residents between the hours of 7.30 am and 9.00 pm, whilst at night; there is usually one nurse and one auxiliary on duty

Obviously we can only draw general conclusions from this, and are only referring to our own experience, but other remarkable differences include the fact that nursing is better valued and respected by doctors in Switzerland and there is more communication between different health-care professionals in the multidisciplinary team. Although this may depend upon the work setting and may only be our own experience given that we have little professional experience of working as fully qualified nurses in Spain. We can relate to this aspect though, the greater amount of time available not only to carry out technical tasks, but also to talk and communicate with patients and their families, make ourselves available to them, and liaise with different professionals participating in their care.

Differences in access to ongoing professional development and training are another aspect that we might stress, since we are currently receiving training in oncology and palliative care at the Haute Ecole de Santé de Genéve. It is likely that this is made possible by the fact that we have an open-ended contract with our employers and have both economic and professional stability in our jobs as a result. Undertaking this post-graduate course has allowed us to discover the theory of 'human becoming' developed by Rose-Marie Rizzo Parse, a humanistic theory focused on the individual person. Practicing according to this theory allows us to approach people and their families from a new and deeper perspective as we did six years previously at the Casa Madonna dell'Uliveto Hospice in Italy although they did not use the theory specifically in their daily

work. The course has also given us the opportunity to observe training at the Institut Català d'Oncologia (the Catalan Oncology Institute) in Barcelona, with the aim of using new and different ways of nursing in our daily practice. Thus, at the present time, both our professional and personal objectives are interlinked, and focus upon oncology and palliative care nursing which we hope to use on our return to Spain when our travels (and our adventures) are over!

# The Experience of Undertaking Doctoral Study in the UK

*Maria Arantzamendi. MSc. RN.*
*Lecturer at the School of Nursing of the University of Navarra. E-mail: marantz@unav.es*

`Life can take you in many directions and you seldom know in advance where it may lead you. When I decided to study nursing, I was very clear that I was going to care for ill people because that was my view of nursing. However; after finishing my degree and spending some time as a staff nurse working with cancer patients in Spain, I realised that the way to improve the quality of care provided to my patients was to continue my education. This led me to enrol on a Master's degree in oncology at the University of Glasgow and following this, to continue my studies at doctoral level at King's College in the University of London.

When deciding to continue my studies, the possibility of undertaking a PhD in Spain was not available, and after considering the options internationally, I decided to continue my postgraduate education in the United Kingdom (UK) because the quality of nursing education in this country was well known. In addition, coming to the United Kingdom offered the opportunity to get to know another culture, broaden my horizons and improve my English, the main language used to disseminate the results of nursing research internationally. I also thought that the United Kingdom was a good choice as there was a more established research culture and tradition within nursing. I initially did my Masters degree in nursing at the University of Glasgow (Scotland) because they offered some modules on oncology. This gave me the chance to gain in-depth knowledge of an area which fascinated me and enable me to improve the quality of care provided to the patients I had being caring for in Spain until that point.

Living in a country with a different culture, language and education system was a challenge. I was used to an education system based primarily around lectures, but in the UK I learned to find my own way reviewing literature and working on the themes I was asked to consider for different subjects. Knowledge was acquired in a more active way, and this led me to become much more mature in my way of thinking and expressing my views. At first it was not easy to get used to the terminology used in the different courses as there was a tendency to use abbreviations to talk about nearly everything. Not knowing their meaning made it difficult for me to follow the sessions, but little by little I managed to develop my understanding and participate actively in the classes. I learned how to find and select scientific evidence about the themes I was interested in, and to critically analyse the information obtained.

This was just the first step however. When I finished the Masters degree there was a wider world existing beyond the boundaries I had imagined until then. I was more aware of the need to plan and carry out research, to contribute in some way to the existing knowledge base, and to the development of nursing in Spain. My desire to continue my education and provide evidence of the value of nursing work was (if possible) even greater than when I started, and thus, I decided to complete a doctoral degree.

I continued to be interested in the area of oncology, but my focus was shifting towards the experiences of nurses working in acute hospital areas when caring for terminally ill people. I remembered the terminally ill patients who were admitted to the hospital unit where I worked and how it affected us when they died. We took care of them but it seemed an 'invisible' labour. The memories of my colleagues and our day to day work at the unit made me wish to make visible and provide evidence of this 'invisible' work, and this was going to be the subject of my doctoral thesis.

As the topic of my thesis was related to terminally ill patients and palliative care, I wanted to do my doctoral degree at a university that had an established research team in this area. I therefore applied to carry out my doctoral thesis at King's College, part of London University, and still remember the first meeting with my PhD supervisor after my proposal was accepted. It seems like yesterday when she told me that the proposal was very interesting but that several doctoral theses could come out from it! I had to narrow my proposal down, but how was I going to leave something behind when I found all of the elements proposed interesting and worthy of study? I have to admit that in my eagerness to provide evidence of nurses' work, it was an ambitious proposal and was not realistic, but it covered all my interests.

After working together with my supervisors and carrying out an extended literature review, I did manage to narrow down the research question for my doctoral thesis which considers what caring for terminally ill patients involves for hospital nurses working in acute areas. This is specified in three objectives: to explore the daily work and the experiences of nurses who care for terminally ill patients on acute hospital wards, to understand their perspective of the challenges in caring for terminally ill patients, and to describe the personal and professional factors influencing nurses' experiences with these patients.

These objectives led me to use a mixed method design combining both qualitative and quantitative methodologies (1). First I conducted an observation period to explore the daily work of hospital nurses caring for terminally ill patients. Then on the basis of my preliminary observational findings, I carried out several interviews to obtain nurses' perspectives on the topic. Finally, with all the data and the literature reviewed, I developed a questionnaire to conduct a regional survey to explore the situation in Navarra – one of seventeen autonomous regions of Spain - to study the relationship between personal and professional variables affecting nurses and their

experience of caring for terminally ill patients in acute settings.

Undertaking a doctoral thesis in the United Kingdom is a challenge. This entailed familiarizing myself with a more developed research tradition and learning about different data collection and analysis methods. It is a process in which many people are involved and I have met people from all over the world with whom I was able to share concerns and seek advice. Moreover, I have managed to make my project a reality with the collaboration and guidance of my supervisors and other experts in this area. The PhD also entailed talking to nurses from whom I learned a great deal as they shared their experiences and opinions with me in the course of many interesting conversations, and I thank them here for their valuable contribution to my studies.

As in any process, there are many ups and downs and mood changes, but undertaking a PhD is definitely a worthwhile experience. I carried out data collection in Spain with the intention of contributing to the knowledge-base and care situation in my own country but the continuous use of two languages, English and Spanish required a great deal of effort on my part. It was the best way however, to contribute to the knowledge-base in Spain in addition to developing general nursing knowledge.

I have learned a great deal, both personally and professionally from carrying out this project, and now have a better sense of my abilities and limitations. I am also aware of what it is known about my topic of interest and what the areas for future research are. I am not as ambitious as when I started my PhD, and know that I will not change the world. However; I do hope to contribute to our knowledge about the work involved in caring for terminally ill patients in acute settings and make more apparent, the 'invisible' work in which nurses are involved on these wards.

The Bologna Declaration makes reference to the European Higher Education Area which opens up new possibilities and entails many changes for nurse education in Europe. It is important to highlight how the adoption of a system of easily comparable degrees throughout Europe based on two main cycles (graduate and postgraduate) with transferable European credits facilitates greater geographical mobility (2). In Spain, this involves the possibility of carrying out official postgraduate education and gaining access to second and third cycles of education. This is now a reality in my own country and Spanish nurses can now undertake Masters and Doctoral study without having to leave the country of their birth; but my experience of studying in the United Kingdom has allowed me to develop both personally and intellectually. This will allow me to transfer what I have learnt to a Spanish context and contribute to the development of nursing research in my own country whilst collaborating with nurses and other health-care professionals at an international level.

**References**
(1) Creswell JD, Plano Clark VL: Designing and conducting mixed methods research. London, 2006, Sage Publications Ltd.

(2) European Higher Education Area. Joint Declaration of the European Ministers of Education convened in Bologna on June 1999.
http://www.hefce.ac.uk/partners/world/bol. Accessed: 17th April of 2007.

# Cancer Care in Spain:

## a Patient´s Perspective.

*H.S.*

My husband and I sold our home in England five years ago and retired to Javea, a small town with beautiful beaches, and now have Spanish residency. We love Spain and its people, their many customs and way of life and also, of course, the beautiful weather.

In June, 2006 I developed a lump in my neck followed in July by a large lump in my breast. I went to see my local Spanish doctor and he referred me to the oncology out-patient department in Denia. Whilst awaiting these two appointments – within the space of a couple of days - I became very ill as my immune system was collapsing and my doctor sent me to the Emergency Department at the local hospital. I was very apprehensive as to how I would cope with my hospital experience since, although I had been trying to learn some Spanish, I had very little conversational ability and only had a basic knowledge of the language. I need not have been so worried however, as the care and attention I received in both hospitals since then have been superb.

I spent five weeks at my local Spanish hospital where I received many blood transfusions and underwent a series of X-rays, scans and biopsies. Whilst there, I received first class care and treatment from every members of staff, including doctors, nurses, nursing assistants etc. It may be that my faltering attempts at speaking Spanish helped me during this time as everyone I came in contact with was extremely kind and helpful.

As a result of the diagnostic tests, I was diagnosed with lymphoma and two secondary tumours, and continued my treatment at the hospital in Valencia where I received an intensive course of chemotherapy. I had to leave my house and go to the hospital in Valencia, some distance away for 6 days every 3 weeks or so, and once again the care I received was excellent. My doctors explained the treatment I was receiving and monitored my progress, answering my questions on a daily basis. It was a bonus for me that a number of the doctors and nursing staff had a good knowledge of English so my lack of fluent Spanish was not an insurmountable problem.

I had regular appointments with the Spanish doctors at my local hospital during each of the 2 week breaks between my chemotherapy treatments where blood samples were taken and I was updated on the progress of my treatment. My medication was reassessed during these visits and I was reassured by the obvious liaison between doctors at my local hospital and the Valencia cancer centre.

As an overseas resident, I have been genuinely impressed with the medical facilities and standard of nursing care available in Spain, and by the overall cleanliness of the units in which I have been treated. This and the studious attention of the doctors and nurses to aseptic techniques adds to one's feeling of security and being cared for in a safe environment.

If I have one complaint about my experience of care in the Spanish health system, it would be that meals were always cold when they arrived on the ward, but a very good Spanish friend assured me that Spanish people quite enjoy their meals like this, and not piping hot like the British!

The hospital system in Spain is very different from that in the U.K. as family members are also heavily involved in caring for their relatives' welfare, but the system works extremely well. My husband and I have no family living in Spain, and so I was on my own a lot of time I was in hospital as it was impossible for my husband to be with me the whole time. This was not a problem however, as the staff were superb and when sharing rooms with Spanish patients, their families were all very friendly and helpful towards me, and we had many pleasant times.

In one sentence, my experience of the Spanish health system and its hospitals has been excellent!

# The NCCN guideline for distress management:

## A case for making distress the sixth vital sign

*Adapted with permission from a commentary written by JC Holland and BD Bultz which appeared in Journal of the National Comprehensive Cancer Network 2007; 5(1): 3-7*

The psychosocial care of patients has traditionally been seen as separate from routine medical care and has been criticised as being "soft" and lacking evidence. This traditional perspective continues in many settings despite the fact that patients and families state that emotional care is highly values. The question of how to integrate psychosocial care into routine cancer care has also been an issue, partly because of the stigma associated with cancer.

In 1997, the National Comprehensive Cancer Network (NCCN) established a multidisciplinary panel to examine how to integrate psychosocial care into routine care. Using a simple question to ask patients about psychosocial concerns, the NCCN panel found that distress was the best umbrella word to represent the range of emotional concerns patients with cancer experience and that it did not carry the stigma of other words sometimes used for emotional symptoms.

In 2004 the Canadian Federal Government's public health agency, Health Canada-Canadian Strategy for Cancer Control, approved emotional distress as the 6th vital sign. Drs. Holland and Bultz propose that this practice should be considered in the United States to ensure that psychosocial distress is routinely assessed as part of cancer care and managed according to the NCCN distress management guideline. Following is a presentation of the potential benefits that can accrue for patients, families, and the health care system through the routine assessment of psychosocial distress.

**NCCN Guidelines for Distress Assessment**
Distress can be considered to range from normal fears, worry, and sadness to disabling problems such as clinical depression, generalized anxiety, panic, isolation, or a spiritual or existential crisis.

The NCCN guideline provides an algorithm to quickly identify patients with significant distress. Similar to the 0 to 10 scale for assessing pain, a visual analogue screening approach can be used to help patients rate their distress, becoming the 6th vital sign. Patients can be asked, "How is your distress on a scale of 0 to 10?" A score of 4 or higher (a first-level inquiry) is a trigger for the oncologist or oncology nurse to ask additional questions (a second-level inquiry) to determine the cause of distress and refer the patient to the proper psychosocial or supportive care service. The Distress Thermometer is accompanied by a Problem List, in which patients are asked to note the nature and source of their distress (physical, social, psychological, or spiritual) which assists health care professionals to arrange a referral to the appropriate resource.

Several studies have been done to establish the reliability and validity of the Distress Thermometer as a screening instrument for distress. Patients are comfortable using the Distress Thermometer and Problem List and physicians see these tools as useful checklists to prompt and guide questions about physical and psychological symptoms.

In 2003, the NCCN Distress Management Panel published more fully developed standards for psychosocial care and distress management, which established for the first time a minimal set of quality measures for managing distress:
Distress should be recognised, monitored, documented, and treated promptly at all stages of disease;
All patients should be screened for distress during the initial visit, at appropriate intervals, and as clinically indicated, especially with

changes in disease status such as remission, recurrence, or disease progression;
Screening should identify the level and nature of the distress;
Distress should be assessed and managed according to clinical practice guidelines.

**The Problem of Distress in Cancer Patients**
Distress clearly occurs at a significant level in at least one third of cancer patients, with frequency and severity increasing with advanced stages of illness. A large study conducted at John Hopkins found that 35% of patients had significant levels of distress. The rate for patients with lung cancer was greater, approximately 45%. A study conducted in Alberta, Canada in almost 3000 patients found high levels of fatigue in 49% of patients, pain in 26%, anxiety in 24% and depression in 24%. In a Jordanian sample of hospitalised cancer patients, the prevalence of distress was 70%. Similar overall rates have been reported in other parts of the Middle East, several European countries, South American, and Asia.

**Economics of Psychosocial Care**
Although clinical studies have found that patients benefit from psychosocial care, fewer than 5% of distressed patients in busy clinics are diagnosed with this condition and receive any psychosocial treatment. Studies have shown that timely psychosocial care can be delivered without increasing overall cost. For example, a randomized Canadian study showed a 22% decrease in expenses to the medical system as a results of psychosocial intervention in women with breast cancer and a meta-analysis of 90 studies showed that medical costs were offset when psychosocial care in medically ill patient improved.

In 1993 the then Executive Director of the National Cancer Institute of Canada stated that the most significant advance in cancer treatment in the past decade has occurred in psychosocial care. However, emotional care of the cancer patient still has received only minor recognition within the formal cancer care system – a policy which clearly must change.

**Summary**
Recognizing that the people part of cancer care is a vital component of a compassionate high-quality cancer system makes ethical, emotional, and economic sense. A simple way to screen for distress is to use the single-item question recommended by the NCCN. Drs. Holland and Bultz propose that emotional stress should be declared the sixth vital sign to ensure that distress management, like pain management, becomes a routine part of cancer care.

More about the NCCN Guidelines on Distress Management can be found at the NCCN website at the following address:
www.nccn.org/professionals/physician_gls/PDF/distress.pdf

# SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

**Extreme distress** ●——————————————● **No distress**

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

| YES | NO | Practical Problems |
|---|---|---|
| ❑ | ❑ | Child care |
| ❑ | ❑ | Housing |
| ❑ | ❑ | Insurance/financial |
| ❑ | ❑ | Transportation |
| ❑ | ❑ | Work/school |
| | | **Family Problems** |
| ❑ | ❑ | Dealing with children |
| ❑ | ❑ | Dealing with partner |
| | | **Emotional Problems** |
| ❑ | ❑ | Depression |
| ❑ | ❑ | Fears |
| ❑ | ❑ | Nervousness |
| ❑ | ❑ | Sadness |
| ❑ | ❑ | Worry |
| ❑ | ❑ | Loss of interest in usual activities |
| | | **Spiritual/religious concerns** |
| ❑ | ❑ | Other Problems: |

_____

| YES | NO | Physical Problems |
|---|---|---|
| ❑ | ❑ | Appearance |
| ❑ | ❑ | Bathing/dressing |
| ❑ | ❑ | Breathing |
| ❑ | ❑ | Changes in urination |
| ❑ | ❑ | Constipation |
| ❑ | ❑ | Diarrhea |
| ❑ | ❑ | Eating |
| ❑ | ❑ | Fatigue |
| ❑ | ❑ | Feeling Swollen |
| ❑ | ❑ | Fevers |
| ❑ | ❑ | Getting around |
| ❑ | ❑ | Indigestion |
| ❑ | ❑ | Memory/concentration |
| ❑ | ❑ | Mouth sores |
| ❑ | ❑ | Nausea |
| ❑ | ❑ | Nose dry/congested |
| ❑ | ❑ | Pain |
| ❑ | ❑ | Sexual |
| ❑ | ❑ | Skin dry/itchy |
| ❑ | ❑ | Sleep |
| ❑ | ❑ | Tingling in hands/feet |



## PSYCHOSOCIAL DISTRESS PATIENT CHARACTERISTICS a

Patients at increased risk for distress b

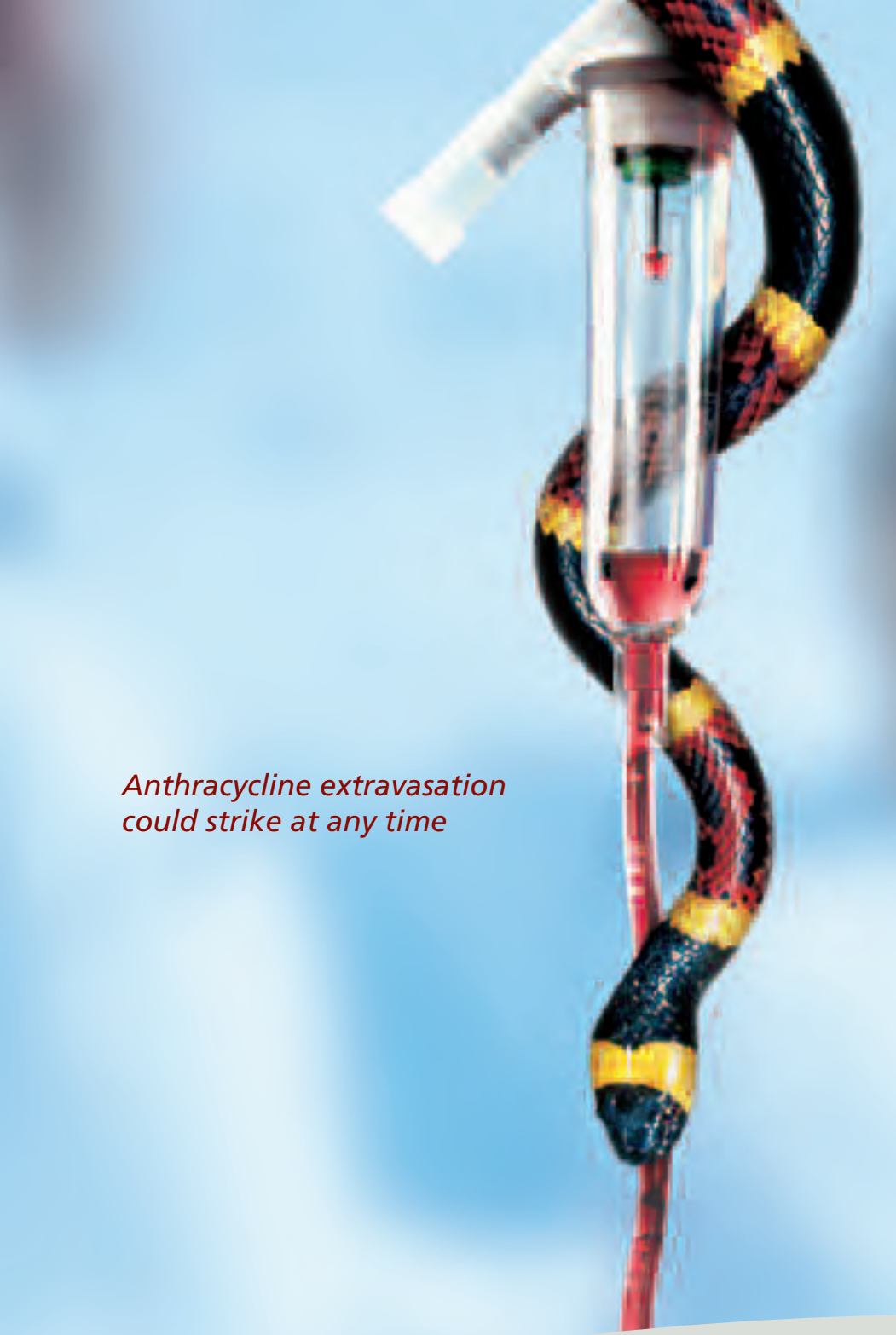
- History of psychiatric disorder/substance abuse
- History of depression/suicide attempt
- Cognitive impairment
- Communication barriers c
- Severe comorbid illnesses
- Social problems
- Family/caregiver conflicts
- Inadequate social support
- Living alone
- Financial problems
- Limited access to medical care
- Young or dependent children
- Younger age; woman
- Other stressors

Periods of increased vulnerability

- Finding a suspicious symptom
- During workup
- Finding out the diagnosis
- Awaiting treatment
- Change in treatment modality•
- End of treatment
- Discharge from hospital following treatment
- Stresses of survivorship
- Medical follow-up and surveillance
- Treatment failure
- Recurrence/progression
- Advanced cancer
- End of life

**Note: All recommendations are category 2A unless otherwise indicated.**
**Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.**

a For site-specific symptoms with major psychosocial consequences, see Holland, JC, Greenberg, DB, Hughes, MD, et al. Quick Reference for Oncology Clinicians: The Psychiatric and Psychological Dimensions of Cancer Symptom Management. (Based on NCCN Distress Management Guidelines). IPOS Press, 2006. Available at www.apos-society.org
b From the NCCN Palliative Care Clinical Practice Guidelines in Oncology. Available at www.nccn.org
c Communication barriers include language, literacy, and physical barriers.



*Anthracycline extravasation could strike at any time*

**Savene™ – Brief prescribing information**
(based on the UK Summary of Product Characteristics SPC)
Please refer to the SPC for full prescribing information.
Each Savene™ box contains 10 vials of Savene™ (dexrazoxane) Powder (10 x 500 mg each) and 3 bags of SaveneTM Diluent (3 x 500 ml each) for infusion. **Indications:** Treatment of anthracycline extravasation. **Dosage and administration:** Administration of Savene™ should begin as soon as possible and within 6 hours after the accident. Savene™ should be given as an intravenous infusion once daily for 3 consecutive days according to body surface area: day one, 1000 mg/m2; day two, 1000 mg/m2; day three, 500 mg/m2. For patients with a body surface area of more than 2 m2 the single dose should not exceed 2000 mg. Cooling procedures such as ice packs should have been removed from the affected area at least 15 min before administration. Before infusion, Savene™ Powder must be reconstituted with sterile water before further dilution in Savene™ Diluent. Savene™ is not recommended in children and patients with renal and hepatic impairment. Safety and efficacy have not been evaluated in the elderly. **Contraindications:** Hypersensitivity to the active substance or to any of the excipients, women of childbearing potential not using contraceptive measures, lactation or concomitant vaccination with yellow fever vaccine. Precautions: Local examination should be performed on a regular basis after treatment until resolution and haematological monitoring should be undertaken regularly. Savene™ should be administered only under the supervision of a physician experienced in the use of cancer chemotherapeutic agents. Routine liver function tests are recommended before each administration of Savene™ in patients with known liver function disorders. Patients with renal dysfunction should be monitored for signs of haematological toxicity. Men are advised not to father a child during and up to 3 months after treatment. Women of childbearing potential must use contraceptive measures during treatment. This product is generally not recommended in combination with live attenuated vaccines or with phenytoin. Dimethyl sulfoxide (DMSO) should not be used in patients who are administered Savene™. As the Savene™ diluent contains potassium (98 mg/500 ml) the plasma potassium level of the patient must be closely monitored in patients at risk of hyperkalaemia. It also contains sodium (1.61 g/500 ml) which may be harmful to patients on a low sodium diet. **Interactions:** Interactions common to all cytotoxics, which may also react with oral anticoagulants. Concomitant use of immunosuppressives such as cyclosporine and tacrolimus receive extra consideration due to excessive immunosuppression. **Pregnancy and lactation:** Savene™ should not be administered to pregnant women unless clearly necessary. Women of childbearing potential should use contraceptive measures during treatment. Mothers should discontinue nursing during Savene™ therapy. **Side-effects:** Very common: nausea, injection site pain, postoperative infection. Common: vomiting, diarrhoea, stomatitis, dry mouth, pyrexia, injection site phlebitis, injection site erythema, fatigue, injection site induration, injection site swelling, peripheral oedema, somnolence, infection, neutropenic infection, wound complication, weight decrease, decreased appetite, myalgia, dizziness, sensory loss, syncope, tremor, vaginal haemorrhage, dyspnoea, pneumonia, alopecia, pruritus, phlebitis, thrombophlebitis superficial, limb venous thrombosis. All adverse reactions have been rapidly reversible. More rarely increased concentrations of liver enzymes (ALT/AST) have been reported. Refer to the SPC for additional information. **MA:** EU/1/06/350/001. Date of Preparation: January 2007. TopoTarget A/S Fruebjergvej 3, DK

TOPOTARGET
*Practical Answers For Cancer*

# Be prepared

Anthracycline chemotherapy has long been a cornerstone of cancer therapy. However, it carries a relatively rare but potentially devastating risk: extravasation.

Anthracycline extravasation can result in severe injuries including ulceration, necrosis, slow-healing lesions, serious joint damage and may not only require surgical intervention, but also long-term suspension of cancer chemotherapy[1].

**Now there is an Antidote* - Savene™ from TopoTarget.**

Savene™ has shown a clinical success rate of > 98% in biopsy proven anthracycline extravasation. It not only avoids the need for surgery but also allows to continue chemotherapy without interruption[2].

Savene™ is available as an 'on-site-ready-to-use' emergency kit – allowing you to always prevent an accident from becoming an emergency.

www.savene.com

savene™
dexrazoxane

***The Antidote***
*to anthracycline extravasation*

* Effective against doxorubicin, epirubicin, daunorubicin, idarubicin

1. Mouridsen H.T. et al. Treatment of anthracycline extravasation with Savene (dexrazoxane): results from two prospective clinical multicentre studies. Ann Oncol. 2007; Volume 18 Issue 3:546 - 550. 2. Mouridsen HT, et al. Treatment of anthracycline extravasation with Savene (dexrazoxane). Results from two prospective clinical multicenter studies. ESMO late-breaking Abstract Session: 2 Oct 2006.

# 2007 Excellence in Patient Education (EPE) Award!

*Jan Foubert, Chair of the jury of the EPE award 2007*

Four projects have been submitted for this year's Excellence in Patient Education (EPE) Award. Entries covered various areas of the cancer patient experience. The entry from the Netherlands produced a sign guide called "signaalwijzer"; a flip chart, used as a practical tool for use during education sessions about chemo-immunotherapy. This SignGuide Oncology (SGO) was developed by Niek Golsteijn , Netherlands, V&VN Oncology (Dutch oncology nursing society) and makes it possible to learn about a treatment's side effect in a clear and vivid way and works with the aid of pictogram's, especially useful for elderly patients and or patients with limited reading skills.

Other nominations from Ireland included a comprehensive admissions booklet on complementary therapies with the title "understanding cancer and complementary therapies: a guide for patients with cancer". This 88 page booklet includes topics such as choosing complementary or alternative therapies, types of therapies and support resources. Joan Kelly also was nominated for an other booklet "A time to care : caring for someone seriously ill at home", this 40 page booklet's aim is to assist people who want to care for a seriously ill family member or friend at home and this booklet talks about the practical aspects of caring someone who is seriously ill. More information about these booklets can be obtained through the Irish Cancer Society and our colleagues from IANO.

Sara Gardyn from Israel was nominated by the Israeli Oncology Nursing Society for her contribution to the production of 5 information booklets for patients receiving radiotherapy to different parts of the body. The radiotherapy treatment areas include breast, lung and chest wall, head and neck, abdomen pelvis and rectum and prostate gland. The booklets are written in a simple language and presented in a patient friendly format.

**And who is... The Winner!**

With fewer but interesting submission this year, the judges found it difficult to choose one project since not all of the project's were developed in English and English is the common language in the jury but nevertheless, after considerable deliberation, one entry clearly stood out from the rest in terms of its creativity, clarity, comprehensiveness and clear patient focus. We are delighted therefore, to announce that the 2007 EONS Excellence in Patient Education Award has been given to Mr Niek Goldsteijn, Vincent Keijers and Sylvia Verhage (Netherlands) for their SignGuide Oncology entitled, 'Signaalwijzer Oncologie" for the novel way of presenting patient information. Further information about the winning entry and an interview will be included in the next edition of the EONS Newsletter; but in the meantime, we would like to express our sincere congratulations to both Niek and his team and wish them every success in their professional careers.

# International Men's Health Week

Men's Health Week takes place around Father's day (2nd week of June) in many countries worldwide. The event aims to increase awareness of general male health issues and to encourage inter- and intranational institutions and organisations to provide better care for health issues affecting men.

Men's Health Week has grown in size and impact in Europe, firmly establishing itself as a key part of the health improvement calendar in a rising number of countries. Each year the week focuses on a different theme relevant to men's health. In England for example, previous weeks have looked at male health in general (2002), men and sexual health (2003), men and cancer (2004), men and obesity (2005), men and mental wellbeing (2006).
Depending on the country, highlights of the week include:

- Local men's health events, thousands take place each year.
- Parliamentary activities
- Partnership events with stakeholders.

Participating countries include Austria, Denmark, Estonia, France, Finland, Germany, Hungary, Slovak Republic, UK, and Ireland. However, there has been no European focus for the week in Europe until now. In 2007, several of these countries will choose the theme of men and long term health conditions which will also be the theme of the first ever International Men's Health Week at European level.

There are some widely-accepted generalities associated with men's health that are supported both by academic research and the day-to-day experience of health professionals. These generalities are that:

- Men are less well informed about health than women
- Men are less likely to follow advice in relation to the prevention of illness and more likely actively to engage in "risky" behaviour
- Men tend to seek medical help at a later stage than women after the development of symptoms.

This juxtaposition of the evidence in relation to men and women is not, in itself, the crucial point. Comparing men and women is merely a means to recognising something much more important; that poor health in men is not inevitable - at least not to the present degree. In other words, there is plenty of scope for improvement even for intractable and enduring conditions. It should be possible to aim for a future in which men are healthier for longer.

# CANCER IN DIFFERENT CULTURAL CONTEXTS:

## HOW IS THE FAMILY AFFECTED?

*Professor Lea Baider, Director, Psycho-Oncology Sharett Institute of Oncology Hadassah University Hospital*

**Theoretical Background**
Cancer as a chronic illness has become a regular, overt feature of family life, long ceasing to be the private, covert event of an isolated individual. In the United States alone, cancer diagnosis will affect approximately three out of four families. In the Western world, it is relentless in touching one in every three families.5

Every year, an estimated five million people in developing countries die from cancer.10

Ethnicity, culture and religious beliefs strongly influence the individual and family's attitude toward illness, death and dying. Although there is a universal fear of cancer, the association with it arouses images of pain, suffering, guilt, loss of control, fatalism and irreversibility.

In developed and developing countries, there are basic differences not only in resources available for patients suffering from cancer but also in the meaning they attach to the illness experience. The expression of needs and how they are met in different cultural contexts may provide a clearer assessment and insight for initiatives of how cancer care should be perceived and administered.

Recent literature demonstrates that illness preferences vary significantly between different races/ethnicities, including the reluctance of blacks and Hispanics to use hospices, advance directives, and withdraw life-sustaining treatment7 and of Arab Muslims to unnecessarily prolong life.8 In most studies, race/ethnicity remained a significant predictor of end-of-life decisions even when adjusting for demographic and socioeconomic status variables.4

**How families manage cancer**
The nature and intensity of chronicity of cancer in the family is bound by the family's cultural and social meaning of cancer, its capacity and knowledge to deal with the new circumstances, flexibility in spousal roles, open communication of illness, and sharing decisions with healthcare team.

The family's protective mechanisms for confronting cancer include: family trust, mutuality and connectedness; supportive family relationships; emotional expressiveness; open communication; the family's capacity to deal with illness; clear family organization; and tolerance of individual and family system of beliefs.

When a family is confronted with cancer, the psychological risk factors include: intrafamilial conflict, criticism and blame; trauma related to diagnosis and treatment; rigidity and denial; additional external stresses; lack of an extra-familial support system; isolation and loneliness; and lack of family trust.

How is the family affected by cancer in different cultural contexts?
"In western culture, where I previously worked, care is expressed by a firm handshake, eye contact, a smile, a reassuring touch or, perhaps, a prolonged private visit with the patient to have a personal discussion of the problem...
Then I moved to the United Arab Emirates and began to look after a population of Muslim patients.

...The patient arrives with her three sisters and her older brother. All the negotiations begin only with the older brother. It is the family that makes decisions and not the individual patient...

This total change in my life has given me occasion to think long and hard about all the techniques I had used in building rapport and to reexamine them in light of a totally different culture."11

If secular Western ethics of care can be described as rights-based with a strong emphasis on individual rights and autonomy, Islamic ethics of care is based on family ties and obligations toward God.2

In Western countries, should we think of an individual patient as having the exclusive right to make decisions regarding his/her illness, or should we relate to the family as the primary ethical unit of care? As patients encounter the illness as an anomaly and are forced to confront the reality of having cancer, they may turn to their families for support and guidance rather than relying only on themselves as they would under ordinary circumstances.

Awareness and perception regarding illness are shared and negotiated between family members. Socio-cultural understandings of illness include norms regarding how family members are expected to relate and care for one another in the event of illness. They become part of family legacies, which are passed down from one generation to the next.3

**The Muslim Arab family culture in the Middle East**
Are our cultural and social concepts of the "Western family" suitable for understanding non-Western cultures? Are concepts of culture and religion segregated or integrated in a broader system of beliefs and social behavior within the family?

A diagnosis of cancer brought an end to searching for a cure and signalled a time of preparation and waiting rather than intensive treatment. "I must simply wait until God calls me home. There is no chance of getting better, so all I have to do is to wait until the 'home calling'."7

When inquiring about the life expectancy of terminal cancer patients, Muslim Arab families are usually skeptical and disregard definitive responses from healthcare professionals. They are likely to be more comfortable with ambiguous answers and expect that it is all in Allah's hands without ever being able to predict His wishes until the end.1

Only family members contribute significantly to the decisions concerning care. Power relationships in Muslim families vary from one family to another, although generally, parents, older brothers and adult children in descending order, and male spouses have greater decision-making power than the rest of the relatives.
Arab communities remain extremely family oriented, and the "hamula" (extensive kinship) is the basis of family structure. There is a clear and rigid gender differentiation, with families being hierarchical and patriarchal in their structure and orientation. Women are subordinate to men (father-brother-husband). Marital rates have risen to 91% of population (15 years and older), with consanguineous marriages being common and frequent, and divorce virtually nonexistent. There is also endogamy in marriage.

**Muslim Cultural and Religious Values**
Muslim society has a unique value orientation based on laws of the Qur'an.
To maintain harmony is to accept hierarchical relations based on family kinship. The Arab heritage is based on shared loyalty and

unquestionable family authority by male and kinship bonds. Friends and any social contacts are considered secondary to needs. There is a total commitment to family needs, expectations and patterns of behavior.6
Purity and modesty in dress, behavior and speech are expected of all women. A Muslim woman should not expose her body, because it is sacred, to any man except husband, father, brothers or uncles.9

Family behavior towards cancer: varies from myths about causation, divine punishment as attribution, fatalistic behavior, silence – secrecy, denial – isolation, shame, stigma, distrust of physicians, non-compliance, and afterlife as a prevail belief.
Among Muslim Arabs, it is normative behavior for the family to be responsible for the care of the patient in the process of illness and/or impending death. Being a burden to the family is not the family's or the patient's concern. It is expected that the females provide all the caregiving to the patient and to the male family members. When confronted with cancer illness, most Muslim Arabs will not go to nursing homes or hospices. It is perceived as unthinkable and against all the basic norms and values of family care.4

*Are we capable of learning and integrating different modes of cancer care?*
Psychosocial interventions with families during the illness trajectory should be based on the following overarching themes:

1. The family's balance on feelings of acceptance – between isolation, stigma and shame, and openness, mutual adaptation and compassion – within the boundaries of each distinct social culture.
2. The family's capacity to equilibrate between the health patterns of ordinary behavior and the integration of the new life circumstances into the chronicity of the illness threat.
3. Respect and understanding of the family's selective system of belief – religiosity – in their own interpretation of their discreet mode of care in all aspects of life, illness and death.

Are our cultural and social concepts of "family care" appropriate for understanding and comprehending other norms of compassion, other meanings of protection and care within the family, and other divergent systems of belief in the face of a severe threat such as cancer?

Does familial perception of illness and health belong to a universal or confined cultural domain?

... Perhaps...our professional and individual pursuits should aim at integrating the legacy of other cultures as a bridge for mutual trust, help and care...

**References**


- Al-Shahri MZ (2002) The future of palliative care in the Islamic world. West J Med 176: 60-61
- Al-Shahri MZ, al-Khenaizan A (2005) Palliative care for Muslim patients. J Supp Oncol 3: 432-436
- Baider L, Cooper CL, Kaplan De-Nour A. (eds) (2000) Cancer and the Family (Second Revised Edition), John Wiley & Sons, London and New York
- Duffy SA, Jackson FC, Schim SM et al (2006) Racial/ethnic preferences, sex preferences, and perceived discrimination to end-of-life care. J Am Geriatr Soc 54: 150-157
- Global Cancer Statistics. American Cancer Society, August 2004
- Nydell MK (2002) Understanding Arabs. 3rd edition. Intercultural Press, Yarmouth, Maine
- Ramsay S (2001) Raising the profile of palliative care for Africa. Lancet 358: 734-735
- Sarhill N, LeGrand S, Islambouli R et al (2001) The terminally ill Muslim: death and dying from the Muslim perspective. Am J Hosp Palliat Care 18: 251-255
- Sayed MA (2003) Psychotherapy of Arab patients. Am J Psychotherapy 57: 445-459
- Singer PA, Bowman KW (2002) Quality care at the end of life. Br Med J 324: 1291-1292
- Sparling TG (2006) Caring for Fatima. J Clin Oncol 24: 2589-2591


**References not used:**


- Abdel-Fattah M, Zaki A, Bassil M et al (2000) Breast self-examination practice and its impact on breast cancer diagnosis in Alexandria, Egypt. Eastern Mediterranean Health J 6: 34-40
- Haj-Yahia MM (1995) Toward a culturally sensitive intervention with Arab families. Contemp Fam Therapy 17: 429-447
- Harirchi I, Ebrahimi M, Zamani N et al (2000) Breast cancer in Iran: a review of 903 records. Pub Health 114: 143-145
- Kahan E, Ibrahim AS, El-Najjar K et al (1999) Cancer patterns in the Middle East. Acta Oncologica 36: 631-636
- Kobeisy AN (2004) Shame in the context of illness: an Islamic perspective. The Yale J Humanities Med, September 17, 2004.
- Nahla A, Haddad LG (2004) The effect of the health care model in Muslim Arabs. Transcultural Nurs 15: 114-121
- Petro-Nustas W (2001) Young Jordanian women's health beliefs about mammography. J Commun Health Nurs 18: 177-194
- Petro-Nustas W, Mikhail BI (2002) Factors associated with breast self-examination among Jordanian women. Pub Health Nurs 19: 263-271
- Talamantes MA, Lawler WR, Espino DV (1998) Hispanic American: care giving norms surrounding dying and the use of hospice services. Hospice J 10: 35-49

# Presidential Insight:

## An interview with Yvonne Wengström

*Yvonne will conclude her term of office as EONS President in September 2007. We thought it would be interesting for EONS members to get an insider's perspective on her experiences during the last two years.*

*How would you like to be remembered as President of EONS?*
I would like to be remembered as the person who worked hard on developing the infrastructure for the Executive Board since the organisation has grown in a very successful way. I would also like to be recognised as further advancing the political agenda for EONS as this is something I believe is really important in order to influence the provision of health care. EONS, for example, has played a key role in the organisation of the specialist nurses network (ESNO) for political lobby work.

*In your opinion, what has been the single most significant event to impact on EONS development during the 6 years that you served on the EONS Executive Board?*
I think it is a continuum in the plan for EONS development which has been a priority for all Presidents. Despite each President's different focus for their term, I think that each one has supported the development of EONS in a very complementary way.

*You have been involved in the design and implementation of the EONS Strategic Plan. How would you rate the success of the plan in achieving outlined goals to date?*
I don't think that it is in my personality to ever be satisfied, there is always more that could be done. But when I look back I believe that major accomplishments have indeed been achieved to date. One of the most important for the future of EONS is definitely the establishment of the position of Executive Director.

*What professional and personal lessons have you learned during your term as President?*
The EONS President accepts the position to become President several years in advance. It is, therefore, difficult to develop professionally during the time one serves as President. You just never know when the job offer you can't say "no" to will pop up. Personally it has been a very humbling experience to realize the cultural differences between professionals in the European countries which to me, as a Swede, seem to be very clearly communicated but can easily be misunderstood by others.

You have a special interest in the political agenda, how would you describe the actual situation in the oncology arena?

We have a lot of work to do to make a real difference in oncology nursing in Europe. Firstly, the specialty is not recognised in more than approximately half of the EU countries. But I believe that we now have a clear platform to start to lobbying activities in the political arena. However, this is not something we can do in solitude. We clearly need to develop a better collaboration with the national oncology nursing socieites and we also need to collaborate with the patient organisations and the medical organisations in Europe in order to make a bigger impact.

*Governmental policies on the role of pharmaceutical companies in providing financial support to health care professionals and professional organizations may impact on the ability of EONS to provide educational programs in the future. From your experience, do you see this as a reason for concern?*

The collaboration that EONS has had so far with the industry has been proactively driven by us through the developed infrastructure for learning needs analysis we always conduct before any educational programs are undertaken. In this way, the educational initiatives we have undertaken have been generated by the needs of our members. If in the future we would have to apply for funding from foundations, I think that this would be possible with the set up that we have in place. Despite very successful collaborations with the pharmaceutical companies to date, I think that we may have to face and be ready for changes in the future.

*If you were to choose one area or topic on which EONS should concentrate future efforts, what would that be?*
I think we need to focus on our research agenda. We are still in the baby stage of this development and there is so much to do. For one, we need to think about forming special interest groups for different areas in cancer nursing to attract new members to enhance the development of EONS.

*Successfully juggling job, personal life and EONS responsibilities takes a large part of your life, how do you manage this?*
I don't feel very successful in this juggling, but in the long run it has been worth the sacrifice (even my family agrees). I have learned so much during this time, had the opportunity to meet so many fantastic people that share my passion for cancer nursing that any hardship that I might have experienced during my term as President is forgotten very quickly!

*Finally, do you have a message for the EONS membership?*
I would like to share my life motto: The only constant thing in life is change.

# "Viva Las Vegas"

## Highlights from the Oncology Nursing Society 32nd Annual Congress

*Jane Bryce, MSN, Oncology Clinical Nurse Specialist Clinical Trials Unit, National Cancer Institute Naples, Italy*

The 32nd annual congress of the Oncology Nursing Society (ONS) took place from 24 –27 April in the Mandalay Bay Convention Center in Las Vegas. More than 6000 oncology nurses from all over the world attended the event. The opening ceremonies kicked off with a VIP entrance to acknowledge international nurses attending the event followed by the local ONS host chapter parading in to the tune of "Viva Las Vegas", an old Elvis tune made even more festive with an impersonator encouraging a sing-along.

I want to mention two important highlights from the opening ceremony. First, our own Jan Foubert was honoured during the Award Ceremony with the distinguished International Award for

Contributions to Cancer Care, as recognition for his outstanding contributions to cancer care as clinician researcher, educator and leader. Second, ONS President Georgia Decker spoke of a movement of the American Medical Association and other physician groups to reduce the scope of practice of advanced practice nurses, including oncology nurses. Decker described the ONS response to this threat to both our profession and our patients, and encouraged ONS members to become actively involved in health policy advocacy at a local, state and federal level. A special session entitled "Scope of Nursing Practice Under Attack: "Beware of AMA Efforts in Your State" was held during the Congress.

The Congress was packed with 4 days of instructional, discussion and research sessions, as well as meetings with special interest and focus groups. On Tuesday, in an instructional session on palliative care, Cyndi Cramer reviewed some of the common barriers that impede the transition to palliative care, and compellingly argued the case for a shift of focus from aggressive acute care to aggressive palliative care focused on patient goals, communication and continued presence. Betty Ferrell discussed the preparation of nurses for roles in palliative care and as advocates in transforming cultures of care, and presented her research on the moral distress of nurses who witness medically futile care.

A session on Putting Evidence into Practice (P.E.P.) was also held on Tuesday where Barbara Gobel and Janelle Tipton spoke of the ONS P.E.P project and development of the practical quick reference cards. The P.E.P. cards summarize the strength of evidence available for nursing interventions on specific topics. There are currently 10 P.E.P. cards available: caregiver strain and burden, constipation, depression, dyspnea, fatigue, mucositis, nausea and vomiting, peripheral neuropathy, prevention of infection, and sleep-wake disturbances. Case studies were presented where nurses could use the resources to address patient problems and plan care. The application of evidence-based guidelines in practice and monitoring of nursing-sensitive patient outcomes was also one of the most frequent topics during the podium sessions. A commonality among the successful programs that were presented was that they were nurse-initiated, multidisciplinary, supported by management, and linked to measurable outcomes.

On Wednesday, a Bench to Bedside lecture on nanotechnology in oncology was given by Mauro Ferrari and Catherine Handy. Nanotechnology is the applied multidisciplinary science of engineering of biological systems at the molecular level. Dr. Ferrari discussed the application of nanotechnology in cancer detection (from ongoing surveillance of biological fluids), diagnosis (molecularly targeted imaging), and treatment (personalized and highly localized to the lesion). Dr. Handy discussed nanoparticle albumin-bound (nab) paclitaxel and how it is currently being used to deliver high concentrations of paclitaxel directly into tumor cells. Some of the future promises of "nanotech" are to permit the delivery of multifunctional targeted therapies which overcome biobarriers and are able to direct therapy only where it is needed.

An advanced instructional session on multi-site research for nurse researchers was presented by Barbara Cochrane and Joan Westendorp. This presentation reviewed progress on the ONS strategic plan to facilitate multisite research, through engagement of nurses in various roles and settings, through development of professional research partnership models, and through the translation of research findings into practice. Core competencies have been developed for various roles within a framework that has research leadership at its center supported by the many components of successful research such as data, fiscal and operational management, dissemination and translation, and facilitation and support for subject participation. These competencies were further detailed with exemplars from cooperative group studies, the Women's Health Initiative, and Frances Lewis' nursing research study "Enhancing Connections." The session concluded with a stimulating discussion of the scientific and professional opportunities available through involvement in multi-site research.

Another recurring theme at Congress was survivorship care. There is a mandate to develop programs to meet the needs of the more than 10 million cancer survivors living today in the U.S. In a session on Wednesday, Boyajian, Landier, and Houlihan presented a clinical program for survivorship care for adult and pediatric survivors, demonstrating their experience at the Survivor Program at Memorial Sloan-Kettering Cancer Center, the Childhood Cancer Survivorship program at the City of Hope, and community-based collaborations with the Lance Armstrong Foundation. Survivorship issues were also addressed in various podium sessions. For survivors of childhood cancers, Landier, Wilson, and colleagues developed an educational template that permits nurses to tap into the large amount of patient education available regarding health risks and health protective behaviors and tailor it to meet individual survivor's needs. Long-term follow up of breast cancer patients is undergoing transition to breast cancer survivor care, where long or late term symptom management is only one of many issues that nurses must address. In a breast and ovarian cancer podium session on Friday, Anne Reb presented her research on hope in advanced ovarian cancer patients. She found that two key variables for patients, perceived support and control, were the major factors in sustaining hope.

During the congress, I also had the opportunity to participate in two Special Interest Groups (SIG) meetings (Clinical Trial Nurses, and Breast Care), the Advanced Nursing Research SIG reception and one focus group (Evidence-Based Practice Change). There are 30 active SIGs in ONS and they provide a great opportunity for networking with colleagues with similar interests and expertise, keeping updated on the latest advances, as well as participating in education, research or leadership projects. The Clinical Trial Nurse SIG has written the 2nd edition of the Manual for Clinical Trial Nurses (CTN), to be published this year, and is undertaking a project of role definition of the CTN to be presented in the form of an ONS position statement. The Breast Care SIG (in its 3rd year of existence) is working to promote the certification of the subspeciality of breast care nurses and has an active virtual community benefiting its more than 500 members! Both of these SIGs have presented Instructional Sessions at past ONS Congresses and day-long sessions at the Institutes of Learning. The Advanced Nursing Research SIG is reaching out to other SIGs to foster collaborative and mentoring research relationships, which is a wonderful opportunity for ONS members to learn from our nurse scientists and leaders.

The ONS Congress was a great opportunity to recharge, reconnect, and renew our enthusiasm and focus as oncology nurses. And yes, there was even time to reward ourselves with some fun and social time in the unique desert city of Las Vegas.

EUROPEAN ONCOLOGY NURSING SOCIETY

6th • EONS Spring Convention

# GENEVA
## SWITZERLAND
27-29 MARCH 2008

**New ways of working: innovation in cancer nursing practise**
**Nouvelles méthodes de travail: innovation des pratiques de l'infirmerie en oncologie**
**Neue wege in der praxis: innovationen in der onkologiepflege**

Conference Chair: Sara Faithfull

**In partnership with the Swiss Oncology Nursing Society**

**Powered by**

Onkologiepflege Schweiz
Soins en Oncologie Suisse
Cure Oncologiche Svizzera

FEDERATION OF EUROPEAN CANCER SOCIETIES
www.fecs.be

# Accreditation News: Development of FaCet

## A User Guide for Development of Educational Programmes

One of the most important educational activities of EONS is the accreditation of continuing education courses. The aim of the accreditation programme is to improve the quality of continuing education courses offered to cancer nurses throughout Europe and to provide a mark of professional recognition. The criteria for accreditation have been updated in line with the EU Bologna agreement and are now more focused on competencies and quality mechanisms. Furthermore, the wide range of educational events and programmes that nurses now attend has made the need for broader EONS educational accreditation.

Members of the EONS Accreditation Council are not only responsible for reviewing and approving applications for accreditation, they also provide help to those developing educational programmes and provide feedback and advice for programme development. A new user guide, Facilitating Cancer Education and Training (FaCET), has been developed to provide information and resources for developing cancer educational courses. This document will shortly be available online.

Applications for accreditation are accepted on the following types of programmes:

- Educational programmes of study: defined as no less than 40 hours of educational study and this may be made up of several smaller modules or delivered as an integrated programme of academic study;
- Educational event: defined as the provision of a scientific meeting, conference, course, workshop or satellite symposium of no more than 40 hours educational study;
- Educational resource for patients: defined as health promotion or education materials aimed at either cancer prevention or supportive and palliative care;
- Distance learning educational programme: defined as education provided remotely using published materials including print, Web or CD-Rom resources.

Detailed information on the EONS Accreditation programme is available at www.cancerworld.org/EONS.

# Reducing the misery of oral mucositis

*Jan Hawthorn*

**"It felt as if my mouth was full of razor blades"**
This description from a cancer patient captures the sort of pain experienced by patients undergoing intensive chemotherapy and radiotherapy if they develop severe oral mucositis (OM).

OM is a particularly unpleasant side effect of chemotherapy and radiotherapy arising from damage to the delicate lining of the mouth and throat. The extent and frequency of mucositis is related to the type of therapy, but for patients undergoing bone marrow transplantation with haematopoietic stem-cell support (HSCT) or irradiation of the head and neck, OM occurs in 70 to 100% of patients (Bellm et al., 2000; Sonis et al., 2001; Rubenstein et al., 2004).

Symptoms range from mild erythema to intensely painful ulcerative lesions (figure 1). While mild cases of mucositis may cause difficulty in eating and drinking, severe cases can compromise all oral intake, prevent conversation, impact upon mood, cause sleep disturbances and leave a patient susceptible to infection. It is no wonder that having severe mucositis has been described as "sheer misery" and patients undergoing transplantation report OM to be the most debilitating effect of their treatment (Rose-Ped et al., 2002).

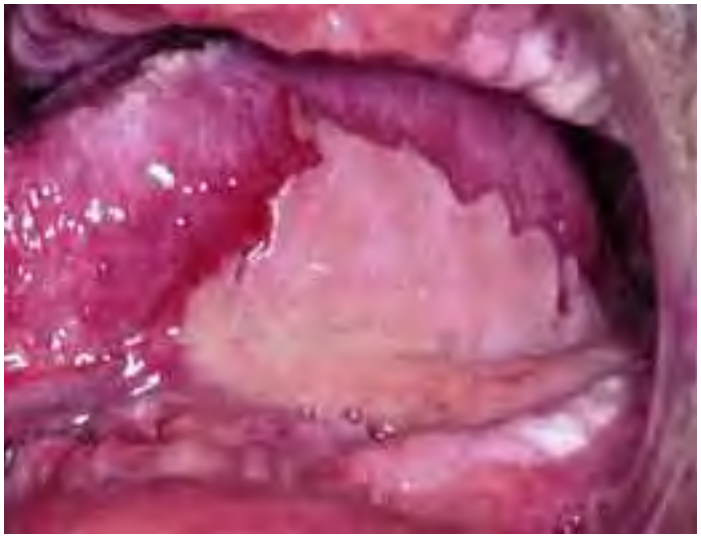


*Figure 1: WHO Grade 3 confluent mucositis experienced by a patient undergoing haematopoietic stem cell transplantation*

Not only does OM impact negatively on quality of life, but there are obvious medical consequences of these symptoms: people who cannot eat are susceptible to dehydration and weight loss and often require parenteral feeding. As the integrity of the oral mucosa breaks down patients are susceptible to bacterial, viral or fungal infections, which may be localised or, in the neutropenic patient, systemic infection leading to sepsis may develop (Elting et al., 2003; Sonis et al., 2004). However, the symptom that seems to most problematic is pain. Pain has obvious impact on quality of life and importantly has been cited as the reason for treatment delays, which can compromise outcome (Kwong et al., 1997; Cox et al., 1992).

This situation presents a challenge to nurses caring for susceptible patients since the majority of widely used interventions for preventing OM are not very effective. A recent Cochrane review (Worthington et al., 2006) assessed information from 71 trials including 5217 patients and involving 29 different interventions for prevention of OM. (This review did not include palifermin, a keratinocyte stimulating factor (see below)). Evidence of any benefit could only be demonstrated for around one third (10) of the agents in use. Mostly, the evidence was weak and only four interventions could be reliably demonstrated to have benefit: amifostine, antibiotic pastilles or paste, hydrolytic enzymes and ice chips. In one case (ice chips) the benefit was only demonstrable in relation to one type of chemotherapy (bolus 5-FU).

The absence of effective options for preventing OM has meant that nurses generally focus on symptom relief, especially pain management (Stone et al., 2005). The cornerstone of pain treatment for OM is opioid-based regimens and morphine administered through a patient-controlled system is emerging as the method of choice (Coda et al., 1997; Rubenstein et al., 2004). While this undoubtedly helps relieve the pain, it also brings a myriad of other problems in its wake. Patients on morphine may experience confusion, sedation, constipation and respiratory depression.

As well as the human misery, OM also has a financial impact on health services since it is associated with increased duration of hospitalisation, increased opioid use, and the use of antibacterial, antiviral and antifungal agents (Elting et al., 2003; Oster et al., 2005).

**New understanding of the pathobiology of mucositis has given us a new agent for preventing OM**
Due to significant advances in understanding the biology underlying oral and gastrointestinal mucosal injury we can now elucidate the steps involved in the pathogenesis of OM. Although there is a continuous progression of events, 5 stages in the development of OM can be described: initiation, primary damage response, signal amplification, ulceration, and healing. (Sonis et al., 2000; 2004).

Understanding this 5-phase model has allowed a different approach to managing OM by allowing scientists to identify the biological agent that can help to prevent or minimise oral mucosal damage, not just to treat symptoms or promote healing. (Donnelly et al., 2003). This biologically active agent is keratinocyte growth factor, which acts to increase epithelial thickness and upregulate cytoprotective mechanisms. By giving this agent before and after the chemotherapy, the mucosa is increased in thickness and more resilient to damage.

Palifermin (Kepivance® Amgen) is a recombinant form of human keratinocyte growth factor (KGF) that stimulates the proliferation, differentiation, migration, and survival of epithelial cells lining the mouth and throat. Palifermin is thought, based on animal studies, to lead to faster replacement of cells killed by cancer treatment, to speed up the healing of mucosal ulceration and protect against mucosal damage at the cellular level, possibly by reducing levels of inflammatory cytokines (Blijlevens, 2006). It is believed that it helps to maintain the integrity of the mucosa throughout the vulnerable period during and following conditioning treatment for HSCT. It is the first FDA-approved therapy for the prophylaxis against OM in patients with haematological malignancies requiring HSCT (haematopoietic stem cell support) (Stiff et al., 2006) - a vulnerable group for suffering OM. Studies are currently underway to investigate the efficacy and safety of palifermin in the solid tumour setting.

Dosing prior to induction chemotherapy is based on the principle of employing proactive measures to protect against OM and shift clinical practice away from the sometimes unsatisfactory situation of only being able to treat the symptoms of established OM.

In a study of 212 patients with haematological malignancies, who were undergoing autologous HSCT (Spielberger et al., 2004), people who received palifermin showed a lower incidence of WHO Grade 3 and 4 mucositis and more patients had only Grade 1 or 2 symptoms. (Table 1 shows the WHO grading system). While 60% of people in the placebo group experienced Grade 4 mucositis, only 20% of those receiving palifermin had grade 4 symptoms ($p<0.001$). Palifermin also reduced the duration of WHO Grade 3/4 mucositis from a median of 9 days in the placebo group to 3 days in the palifermin group; a reduction of 67% ($p<0.001$).

| Grade 0 | Grade 1 | Grade 2 | Grade 3 | Grade 4 |
|---|---|---|---|---|
| None | soreness ± erythema | Erythema, ulcers, and patient can swallow solid food | Ulcers with extensive erythema extensive erythema and patient cannot swallow solid food | Mucositis to the extent that alimentation is not possible |

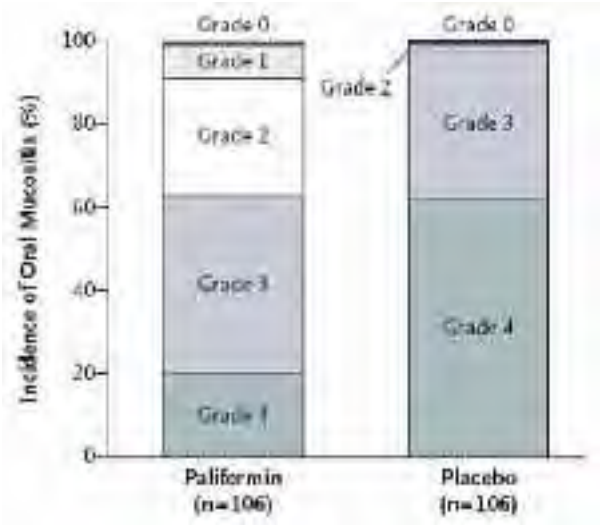



*Figure 2: Oral mucositis incidence (All WHO Grades).*
*Results from a randomised, double-blind placebo-controlled phase 3 study, n=212 (Spielberger et al., 2004).*

According to prescribing information, pre- and post-dosing administration is indicated. Palifermin is therefore given for three consecutive doses before the start of the conditioning regimen and again for three consecutive doses after radiotherapy and chemotherapy. Palifermin should not be administered within 24 hours before, during infusion of, or within 24 hours after administration of cytotoxic chemotherapy.

This dosing regimen does require careful planning of treatment schedules, and may require liaison between departments including the weekend staff. However simple charts are available that assist in treatment planning and also calculating the correct dosage.

Published data show that palifermin is generally well tolerated. In the Spielberger study the most frequently reported adverse reactions in the palifermin-treated patients were rash, pruritus, erythema, mouth and tongue thickening or discolouration, and taste alterations. Most of these adverse events were consistent with the pharmacological action of palifermin on skin and oral epithelium. All were mild to moderate in severity, transient in nature, and not a cause for discontinuation of the study drug.

A recent update from the Mucositis Study Section of the Multinational Association of Supportive Care in Cancer and the International Society for Oral Oncology (MASCC/ISOO) now lists palifermin as one of the three preventative treatments recommended for patients undergoing HSCT (MASSC Clinical Practice Guidelines Update 2005). The other treatments recommended are ice-chips for high dose melphalan and low-level laser therapy, which, as the guidelines state, requires expensive equipment and specialist training, so is not an option for many clinics.

**Nurses' perception of benefits of palifermin for patients**
At a pan-European Nurses Advisory Board1, nurses who have experience with palifermin were asked to share their thoughts and opinions about its effects through discussion around specific questions. The nurses reported that in their opinion:

- Patients receiving palifermin experienced a decrease in both incidence and severity of OM.
- Most patients experienced less pain and lower infection rates compared with patients who had other treatments for OM.
- There was a noticeable decrease in the duration of hospitalization of patients, a decreased use of opioids, and a decreased use of antibiotics.
- Generally, patients receiving palifermin had less difficulty in eating, swallowing and communicating which profoundly influenced their mood, and improved their approach to treatment.
- Patients reported feeling less sleepy since they were taking fewer painkillers, and more inclined to have conversations, both of which made them feel better overall.
- Patients reported less feelings of isolation.

Nurses also reported that their patients experienced similar side effects to those reported in the Spielberger study (Spielberger et al, 2004) (rash, tongue thickening associated with a white coating and altered taste perceptions). Nurse participants stressed the importance of educating patients about possible side effects and reassuring them that they would resolve a few days after treatment with palifermin was ceased and did not need treatment.

It was also important that medical and all nursing staff were educated and did not confuse these side effects with other pathological conditions (e.g. confusing the rash with an allergic reaction or the white tongue with candidal infection) which could lead to inappropriate treatments or discontinuation of palifermin prematurely.

Patients who had experienced OM in previous treatment cycles were especially appreciative of the effects of palifermin and reported a better quality of life than when they had treatment without the inclusion of palifermin. Subjectively, patients seemed to be faring better in the post-transplant period if they had received palifermin.

A somewhat less immediately obvious reported benefit of using palifermin was that it improved nursing morale. Nurses felt that, by contrast to the previous situation, where they had great sympathy for patients with severe OM pain, but felt helpless as they had little to offer other than analgesia, they could now take a proactive approach and felt that they had something really positive to offer their patients. These feelings, along with seeing their patients experience decreased pain and distress, had a really beneficial effect on nurses' morale.

1. These opinions were discussed at a European Palifermin Nurse Advisory Board which was convened to discuss the management of OM and the experiences of nurses during the first six months of palifermin use in clinical practice. The nurses contributing to this board were: Monica Fliedner, Switzerland; Brigitte Baguet, France; Joachim Blankart , Germany; Michelle Davies, UK; Elisabete Henriques, Portugal; Angela Janisch, Austria; Ann-Kristin Karlsson, Sweden; Angela Leather, UK; Ewa Mazur, Poland; Katalin Mihály, Hungary; Liesbet Peeters, Belgium; Agnes Radványiné, Hungary; Blanka Sedlackova, Czech Republic; Katrina Williams, Australia.

This manuscript was sponsored by an unrestricted educational grant from Amgen (Europe) GmbH.

**References**


- Bellm LA, Epstein JB, Rose-Ped A, Martin P, Fuchs HJ. Patient reports of complications of bone marrow transplantation. Support Care Cancer 2000;8:33-39.
- Blijlevens N, Sonis S, Palifermin (recombinant keratinocyte growth factor-1): a pleiotropic growth factor with multiple biological activities in preventing chemotherapy- and radiotherapy-induced mucositis. Annals of Oncology 2006; October 9 [Epub ahead of print].
- Coda BA, O'Sullivan B, Donaldson G, Bohl S, Chapman CR, Shen DD. Comparative efficacy of patient-controlled administration of morphine, hydromorphone, or sufentanil for the treatment of oral mucositis pain following bone marrow transplantation. Pain 1997;72:333-346.
- Cox JD, Pajak TF, Marcial VA, Coia L, Mohiuddin M, Fu KK, Selim HM, Byhardt RW, Rubin P, Ortiz HG, Martin L. Interruptions adversely affect local control and survival with hyperfractionated radiation therapy of carcinomas of the respiratory/digestive tracts. New evidence for accelerated proliferation form RTOG Protocol 83-13. Cancer 1992;69:2744-2748.
- Donnelly JP, Blijlevens NM, Verhagen CA. Can anything be done about oral mucositis? [editorial]. Annals of Oncology 2003;14:505-507.
- Elting L, Cooksley C, Chambers S, Manzullo E, Rubenstein E. The burdens of cancer therapy: clinical and economic outcomes of chemotherapy-induced mucositis. Cancer 2003; 98:1531-1539.
- Kwong DL, Sham JS, Chua DT, Choy DT, Au GK, Wu PM. The effect of interruptions and prolonged treatment time in nasopharyngeal carcinoma. International Journal of Radiation Oncology, Biology, Physics 1997;39;703-710.
- MASCC/ISOO Clinical Practice Guidelines for the Prevention and Treatment of Cancer-Therapy Oral and Gastrointestinal Mucositis Update 2005 http://www.mascc.org/ktml2/images/uploads/Resource_centers/Guidelines_table_12_Oct_05.pdf
- Oster G, Vera-Llonch M, Ford C, Lu J, Khazanov I, Sonis S. Oral mucositis (OM) and outcomes of allogeneic hematopoietic stem cell transplantation (HSCT) [abstract]. In: 17th MASCC International Symposium, June 30-July 2 2005, 2005, Geneva, Switzerland. Abstract 15-107.
- Rose-Ped AM, Bellm LA, Epstein JB, Trotti A, Gweded C, Fuchs HJ.Complications of radiation therapy for head and neck cancers. The patient's perspective. Cancer Nursing 2002;25:461-467.
- Rubenstein EB, Peterson DE, Schubert M, et al. Clinical practice guidelines for the prevention and treatment of cancer therapy-induced oral and gastrointestinal mucositis. Cancer 2004;100:2026-2046.
- Sonis ST, Peterson RL, Edwards LJ. et al. Defining mechanisms of action of interleukin-11 on the progression of radiation-induced oral mucositis. Oral Oncology 2000;36:373-381.
- Sonis ST, Oster G, Fuchs H, Bellm L, Bradford W.Z., Edelsberg, J., et al. Oral mucositis and the clinical and economic outcomes of haematopoietic stem-cell transplantation. Journal of Clinical Oncology 2001;19:2201-2205.
- Sonis ST, Elting LS, Keefe D, Peterson DE, Schubert M, Hauer-Jensin M, Bekele BN, Raber-Durlacher JP, Rubenstein EB. Perspectives on cancer therapy-induced mucosal injury. Pathogenesis, measurement, epidemiology, and consequences for patients. Supplement to Cancer 2004;1995-2025. Published online DOI: 10.1002/cncr.20162.
- Spielberger R, Stiff P, Bensiger W, Gentile T, Weisdorf D, Kewalaramani T, Shea T, Yanovich S, Hansen K, Noga S, McCarty J, LeMaistre CF, Sung EC, Blazar BR, Elhardt D, Chen M-G, Emmanouilides C. Palifermin for oral mucosistis after intensive therapy for hematological cancers. New England Journal of Medicine 2004;351:2590-8.
- Stiff PJ, Emmanouilides C, Bensinger WI, et al. Palifermin reduces patient-reported mouth and throat soreness and improves patient functioning in the hematopoietic stem-cell transplantation setting. Journal of Clinical Oncology, 2006;24:5186-5193.
- Stone R, Fliedner MC, Smiet ACM. Management of oral mucositis in patients with cancer. European Journal of Oncology Nursing 2005; 9:524-532.
- Worthington, H.V., Clarkson, I.E., Eden, O.B., 2006.

Interventions for treating oral mucosistis for patients with cancer receiving treatment. Cochrane Database of Systematic Reviews 3, CD001973.


# Management of Febrile Neutropenia in Paediatric Patients

## Experience from a shared Care System in Ireland.

*Hilary Noonan, Staff Nurse*

Fiona Brady, a colleague of mine, and I work in general paediatric wards in Limerick and Gaway, respectively. These wards provide shared care in conjunction with Our Lady's Children's Hospital (OLCH), located in Dublin. OLCH is the national referral and treatment centre for Childhood Cancers. The cancer unit at OLCH shares care with 16 paediatric units based at local hospitals throughout Ireland. Shared Care Centres provide general support for cancer patients. Their main focus of support is the medical and nursing management of chemotherapy-induced haematological toxicities. The most common dose-limiting haematological toxicity that shared care centres encounter as a result of chemotherapy is febrile neutropenia. Health care professionals should be aware of this, due to the seriousness of a febrile neutropenic episode, the resulting adverse events, and the need for prompt treatment of children presenting with the condition.

In May 2006 Fiona and I attended a TITAN study day (Training Initiative in Thrombocytopenia, Anaemia and Neutropenia). TITAN is a major new training initiative that is spearheaded by the European Oncology Nursing Society (EONS). . TITAN encourages nurses to proactively apply their enhanced knowledge in the prevention, detection and management of these life-threatening conditions. As a result of this study day Fiona and I completed a dissemination project. We developed an education package from a shared care perspective. Our aim was to develop a concise, easily accessible and user-friendly education package on febrile neutropenia for nurses, doctors and other health care professionals.

The febrile neutropenia educational package we developed is based on OLCH guidelines and consists of a power point presentation, a pocket guide on febrile neutropenia and a checklist to be located at the patient's bedside. All items were designed to aid health care professionals in providing consistent day-to-day management of febrile neutropenia in paediatric cancer patients. We carried out two educational sessions to train health care professionals to use these materials. A pre-training questionnaire was used to evaluate health care professionals prior knowledge of febrile neutropenia. A post-training evaluation was used to assess the effectiveness of the educational package and identify further educational needs.

Seventeen nurses, with a broad spectrum of experience, attended the two sessions. The post-training questionnaire showed our sessions were

well received. We were shocked to learn that some nurses were unaware of the potential consequences of febrile neutropenia. They stated that they would now respond more actively to the symptoms of febrile neutropenia. The overall comments emphasised that this package was an excellent, easy to use tool and a much needed resource for staff.

Throughout this project we overcame many hurdles. For example, the cost of printing the pocket booklet by professional printers proved to be very expensive. Fortunately for us with the help of a friend we were able to print the booklet ourselves.

The principal outcome of our project was the production of a user-friendly educational package on febrile neutropenia primarily designed for health care professionals who care for paediatric cancer patients in shared care centres. Pending approval from OLCH, educational sessions in further shared care centres are planned. The impending publication of our pocket guide booklet and educational package aims to maintain and improve the standard of care for febrile neutropenic cancer patients.

I am delighted to inform you that our educational package won both the Irish and European TITAN dissemination competitions. As a result of TITAN we have been offered a great opportunity. We will be presenting our educational package at the ECCO conference in Barcelona in September. Amgen Ireland Ltd. and the Irish Association for Nurses in Oncology whilst supporting TITAN have also been very supportive to us in making our idea become a reality!

# Improve the chances of
# a successful outcome in cancer


NUTRICIA *Oncology*
Optimizing outcomes

# Neulasta® protects your patients from febrile neutropenia

## Use Neulasta® to:

- Minimise the consequences of febrile neutropenia and maximise chemotherapy delivery.[1,2]
- Provide self-regulating protection when patients need it most.[3]

Neulasta®
(pegfilgrastim)

**Optimal protection**

**Neulasta® (pegfilgrastim) Abbreviated Prescribing Information**

Please refer to the Summary of Product Characteristics before prescribing Neulasta® (pegfilgrastim). Neulasta® 6 mg solution for injection is presented in a pre-filled syringe. Human granulocyte colony stimulating factor (G-CSF) is a glycoprotein, which regulates the production and release of neutrophils from the bone marrow. Neulasta® is a covalent conjugate of filgrastim, recombinant human G-CSF (r-metHuG-CSF) with a single 20 kd polyethylene glycol (PEG) molecule. **INDICATION:** Reduction in the duration of neutropenia and the incidence of febrile neutropenia in patients treated with cytotoxic chemotherapy for malignancy (with the exception of chronic myeloid leukaemia and myelodysplastic syndromes). **DOSAGE AND ADMINISTRATION:** Solution for injection presented in a pre-filled syringe containing 6 mg of pegfilgrastim, for single dose use only. One 6 mg dose (a single pre-filled syringe) of Neulasta® is recommended for each chemotherapy cycle, administered subcutaneously approximately 24 hours following chemotherapy. There are insufficient data to recommend the use of Neulasta® in children and adolescents under 18 years of age. **CONTRAINDICATIONS:** Hypersensitivity to pegfilgrastim, filgrastim, *E. coli* derived proteins, or to any excipients. **SPECIAL WARNINGS AND PRECAUTIONS:** The safety and efficacy of Neulasta® have not been investigated in patients receiving high-dose chemotherapy. Limited clinical data suggest a comparable effect on time to recovery of severe neutropenia for pegfilgrastim and filgrastim in patients with de novo acute myeloid leukaemia (AML). The long-term effects of Neulasta® have not been established in de novo AML; therefore, it should be used with caution in this patient population. The safety and efficacy of Neulasta® administration in de novo AML patients aged < 55 years with cytogenetics t(15;17) have not been established. Neulasta® should not be used in patients with secondary AML. The safety and efficacy of Neulasta® for the mobilisation of blood progenitor cells in patients or healthy donors have not been adequately evaluated. Rare pulmonary adverse effects, in particular interstitial pneumonia, have been reported after G-CSF administration. Patients with a recent history of pulmonary infiltrates or pneumonia may be at higher risk. Onset of pulmonary signs such as cough, fever, and dyspnoea in association with radiological signs of pulmonary infiltrates, deterioration in pulmonary function with increased neutrophil count may be preliminary signs of Adult Respiratory Distress Syndrome (ARDS). In such circumstances Neulasta® should be discontinued at the discretion of the physician and the appropriate treatment given. There have been common but generally asymptomatic cases of increased spleen size and very rare cases of splenic rupture in healthy donors and patients following administration of granulocyte-colony stimulating factors. Some cases of splenic rupture were fatal. Therefore, spleen size should be carefully monitored (e.g., clinical examination, ultrasound) and this diagnosis should be considered in patients reporting left upper abdominal pain or shoulder tip pain. Regular monitoring of platelet count and haematocrit is recommended during Neulasta® therapy. Neulasta® should not be used to increase the dose of chemotherapy beyond established dosage regimens. Physicians should exercise caution and monitor appropriately when administering Neulasta® in patients with sickle cell disease and be attentive to the possible association of Neulasta® with splenic enlargement and vaso-occlusive crisis. Transient elevation of leucocyte counts ≥100 x $10^9$/L have been observed in <1% of patients receiving Neulasta® with no attributable adverse events. Elevations were typically seen 24–48 hours after administration. **INTERACTIONS:** Concomitant use of Neulasta® with chemotherapy has not been evaluated in patients. In animal models, concomitant Neulasta® and 5-fluorouracil (5-FU) or other antimetabolites have been shown to potentiate myelosuppression. **PREGNANCY AND LACTATION:** No adequate experience in human pregnancy and lactation. Neulasta® should not be used during pregnancy unless clearly necessary. Do not administer to women who are breast-feeding. **UNDESIRABLE EFFECTS:** The most frequently reported study drug–related undesirable effect was bone pain, which was generally mild to moderate, transient and controlled with standard analgesics. Reversible, mild to moderate elevations in uric acid, alkaline phosphatase and lactate dehydrogenase, with no associated clinical effects, occurred in patients receiving Neulasta® following chemotherapy. Allergic reactions, including anaphylaxis, have been reported both with Neulasta® and its parent compound, filgrastim. **PHARMACEUTICAL PARTICULARS:** Store at 2°C–8°C (in a refrigerator). Do not freeze. Keep container in outer carton to protect from light. Neulasta® may be exposed to room temperature (not above 30°C) for a maximum single period of up to 72 hours. Neulasta® is incompatible with sodium chloride solutions. **LEGAL CLASSIFICATION:** Medicinal product subject to medical prescription. **MARKETING AUTHORISATION HOLDER:** Amgen Europe B.V., Minervum 7061, 4817 ZK Breda, The Netherlands. Further information is available from Amgen (Europe) GmbH, Dammstrasse 23, PO Box 1557, Zug, Switzerland, CH-6301. Additional information may be obtained from your local Amgen office. **MARKETING AUTHORISATION NUMBER:** Pre-filled syringe: EU/1/02/227/001-002. **Date of preparation:** November 2005.

AMGEN®
Oncology

**References: 1.** Ozer H, et al. *J Clin Oncol.* 2006;24(18S part I of II):485s. Abstract 8569. **2.** Vogel CL, et al. *J Clin Oncol.* 2005;23:1178-1184. **3.** Green MD, et al. *Ann Oncol.* 2003;14:29-35.



Amgen (Europe) GmbH
Zug, Switzerland