EBMT NG President’s Introduction

News from the board

Communication & Networking Committee

Multiple Myeloma articles:
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- Nurses to play key role in novel trial network
- Report on the 1st Myeloma Euronet meeting in Romania and visiting the University Hospital in Bucharest

Complementary Therapy Services in Haematology & Transplant Settings

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EBMT NG Paediatric Sub Committee Update

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Dear colleagues

Although we still have 2 months to go before 2010 will finish, the EBMT-NG board and the committees are already looking back upon an intensive and successful year. Over the last few years it has become a habit for the Nurses Group to have a large meeting in September which combines a Nurses Group board meeting with the annual meetings for most of the committees. Each committee holds their individual meeting following an initial group discussion with the board. Another group meeting then takes place at the end of the board meeting. This gives the opportunity for everybody to be well informed and discuss issues and new plans.

So, we did this on the 11th and 12th of September in Manchester and again I am impressed by everybody’s commitment with the EBMT-NG and herewith I would like to thank all the members for their hard work and support during this year. Election time for committee members is imminent and some of the committee members are standing up for re-election so if you are interested in applying for a position you can read more about the nomination process in this newsletter.

The board met with members of the communication, paediatric and research sub committees in Manchester
Vision
EBMT has been in existence for 36 years (26 years for the nurses group) and during this time it has evolved and developed as an organisation. Because of this growth and development the EBMT as an organisation has decided to see where changes in the vision are needed to embrace present and future challenges and to continue to enhance the improvement in outcomes of stem cell transplantation. These challenges include increasing the level of science, advancing clinical practice, changing the organisational structure where required and improving the information structure. It is clear we as a Nurses Group have an important role to play in this vision which is already recognised and integrated by the general board. I will keep you informed through the newsletter and of course during the Annual General Meeting.

Survey
In the preparations of these changes every member has been contacted during the summer period to participate in the membership survey. The questions presented in the survey address the organisation as a whole; however, there were also some nurses specific questions. In total 43 nurses completed the questionnaire. Most of the nurses who responded were very positive regarding increasing the influence of nurses in research within EBMT. They also asked for more training and educational initiatives and this training should focus especially on courses, manuals and guidelines. Something for us as a board to work on with you.

Education
Education has been highlighted as an important issue and although there are a lot of educational initiatives which have already been developed and completed there are others which are still continuing at the moment. Of course education remains vital and we will keep this on the agenda for the future. More concrete plans involve a collaborative working relationship with the Educational Committee.

EBMT 2011 Paris
The Scientific committees have been working tirelessly and have already done a tremendous job in the organisation of the next Annual meeting in Paris. The second announcement has just been published which you can find on the website. Keep in mind the deadline for the abstracts is 24 November. So please have a look at the programme for the meeting and the pre-meeting study day and convince yourself to join us at this beautiful venue in Paris.

I look forward to seeing many of you there.
Au Revoir!

Kindest regards,

Arno Mank
President of the EBMT Nurses Group
Dear members,

The fantastic work carried out within the EBMT Nurses Group would not be possible without the hard work and dedication of our various committee members. Once again some of our current committee members’ terms are due to end in April 2011 following the annual congress in Paris. Many of these members may wish to be nominated to continue their work within the committees but as always we encourage any EBMT NG member who would like an opportunity to work with a committee to put your names forward. I would therefore like to invite any interested and motivated members to put your names forward for nomination. Below is information regarding the forthcoming vacancies and the terms required to fulfil one of these positions.

Firstly one position is available to join the scientific committee. This committee is the organising committee for the annual EBMT nurses meeting as well as the pre meeting study day. The committee already has 6 members and has 3 face to face meetings a year. To view the Terms of Reference (TOR) for the scientific committee click on the following link.

Two positions are available within the research committee. The research committee is dedicated to developing and supporting nursing research in the field of haematology and SCT. The committee recently appointed 3 new members who are already working on some exciting new projects. Applicants for this position should have relevant research experience preferably with some research qualification and educated to masters level. Face to face meetings are twice yearly. Follow link for the research committee TOR.

Finally one position is available within the Communication and Networking Committee. This committee is responsible for the production of the newsletters which regularly keep members informed of the activities of the Nurses Group. They also have responsibility for reviewing the content of the Nurses Group section of the website, a vital role as the website is often the first point of information for nurses wishing to find key information regarding the nurses group activities. This is also a role which will become more and more important along with the ongoing development of the EBMT website as a whole.

All committees will have one face to face meeting during the annual conference and others in various venues around Europe. All other communication will be by e-mail or telephone when required.

Applicants must be motivated and willing to commit time and effort to becoming an active member of these committees. An ability to communicate in and have a good understanding of the English Language both written and spoken is required. Access to e-mail and telephone are important and an ability to travel to the required meetings is necessary. You must also be a member of the Nurses Group or if not become one. Expenses for meetings including travel and accommodation will be covered by the EBMT Nurses Group.

Please send a CV along with a short letter of motivation to Lissa Perteghella at the EBMT Secretariat nurses@ebmt.org no later than 20th of December 2010. Successful applicants will start their term from April 2011 with the first meeting being held during the annual conference in Paris. All nominations will be considered during the EBMT Nurses’ group board meeting to be held on January the 22nd and 23rd. If you would like any further information please contact Michelle Davies michellemhoyle@hotmail.co.uk who will be pleased to discuss these positions.

Yours Sincerely
Michelle Davies, EMBT-NG Secretary
Dear Colleagues

This September the EBMT NG Board met with the Research, Paediatric and Communication and Networking Committees in the beautiful city of Manchester.

Arno Mank as our new EBMT president gave us a warm welcome and opened the meeting which was very successful and productive. It is important for the committees to meet with the board once a year to give a report of their activities and to discuss future plans and developments. Once again many projects have been discussed directly with the board and we were able to get instant feedback and work on them straight away. Subjects discussed included educational initiatives, the new website, introducing new national groups and the upcoming conference in Paris.

For this issue of the NG newsletter we have focused on Multiple Myeloma and would like to thank the following contributors;

Mary Kelly for her article providing an overview of the diagnosis and management of Multiple Myeloma.

Maggie Lai from Myeloma UK for highlighting the new early phase clinical trial network in which you are invited to be involved in.

And, Erik Aerts for his report on joining the 1st Myeloma Euronet Romania and visiting the University Hospital of Bucharest.

Many thanks as well to Jackie Stringer for her article on complimentary therapies. As always your feedback is helpful and much appreciated. If you would like to contribute to the Newsletter please do not hesitate to contact one of us.

We hope you enjoy this issue.

Warm wishes,

Sara
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Sabine
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Multiple Myeloma articles:

We have 3 articles focusing on Multiple Myeloma.

The first article provides an overview of the diagnosis and treatment of Multiple Myeloma.

The second article highlights the early phase trial network set up by Myeloma UK in which you are invited to be involved in, and finally there is a report on the first Myeloma Euronet Romania patient and family day.

An overview of diagnosis and management
By Mary Kelly

Nurses to play key role in novel trial network
By Maggie Lai, Myeloma UK

Report on the 1st Myeloma Euronet meeting in Romania and visiting the University Hospital in Bucharest
By Erik Aerts, Past President EBMT NG Board

An overview of diagnosis and management

By Mary Kelly

Introduction

Multiple Myeloma (MM) is a cancer of the plasma cells in the bone marrow (BM). MM is the second commonest haematological cancer after lymphoma. The cause of MM is unknown; risk factors include age, radiation, agricultural exposures and familial risk. Age at diagnosis varies; the majority are over 50 years, with higher male predominance. MM occurs in all races, incidence is higher among black populations. In Ireland 222 patients are diagnosed each year.

Recent advances in our understanding of the pathophysiology of MM have resulted in improved treatment options, remission rates and importantly, disease free survival. Treatments to halt MM and improvement in supportive therapies have improved quality of life (QOL). However MM remains incurable. This article provides an overview of MM diagnosis and management.

Pathophysiology

MM occurs due to unregulated, proliferation of neoplastic monoclonal plasma cells that accumulate in the marrow. B-cell lymphocytes mature into plasma cells in response to infection. Plasma cells produce and release proteins called immunoglobulins (antibodies) which attack and help kill disease-causing organisms. Each immunoglobulin (Figure 1) molecule consists of two two light chains known as kappa and lambda and two heavy chains defined as five classes of immunoglobulins: IgG, IgA, IgM, IgD and IgE. MM is characterized by abnormal overproduction of one of these immunoglobulins by the malignant clones. This overproduced protein is known as the monoclonal (M) protein. Normally mature plasma cells occupy < 5% of the BM, however in myeloma, there are > 10% mature plasma cells in the BM.

Clinical features

MM is often asymptomatic, 30% of new MM cases are diagnosed incidentally. However patients can present with anaemia, hypercalcemia, elevated erythrocyte sedimentation rate (ESR), renal dysfunction, plasma hyperviscosity or bleeding problems. These findings may be treated as separate medical conditions if MM is not included in the differential diagnosis, often leading to delayed referral, diagnosis and poor symptom control.
MM is defined by the presence of end organ damage (CRAB: Hypercalcemia, renal insufficiency, anaemia and bone lesions). In most patients there is a constellation of clinical, laboratory, radiological and pathological findings. It is important to distinguish other M protein conditions; monoclonal gammopathy of undetermined significance (MGUS) and smoldering myeloma (SMM). Clinically, MGUS has a monoclonal protein without presence of CRAB and with < 10% plasma cells in the BM. MGUS patients have a 1% per year risk of progression and require 3-6 monthly review. SMM defined as M-Protein >30 g/dL and/or 10% or more plasma cells in BM, and absence CRAB features, SMM has a higher risk of progression to myeloma (10% per year - first 5 years), these patients can be observed for years before any active treatment is required.

**Bone disease**

Bone destruction is a hallmark of MM. 90 per cent of patients develop bone lesions (Figure 2). MM patients develop skeletal complications including severe bone pain, hypercalcemia, pathologic fractures and spinal cord compression (SCC) resulting in reduced QOL, serious morbidity and increase mortality. Treatments include, analgesia, surgical intervention, rehabilitation, radiotherapy, anti-myeloma and patient education to protect their bones. Early recognition of bone disease leads to prompt treatment and reduced morbidity. Renal insufficiency

Renal insufficiency is found in 24% of patients and is associated with a poorer prognosis. However, if successfully treated prognosis improves. Fluid hydration of 3 litres daily is recommended throughout the disease course and improves overall survival. Management is multi-focused including adequate hydration, anti-myeloma therapy, prompt management of hypercalcemia, dose adjustment of bisphosphonate therapy, avoidance of nephrotoxic drugs. e.g. NSAID, contrast media and prompt treatment of infections. In addition, patient education on preventative measures is crucial to preserve kidney function.

**Hypercalcemia**

Hypercalcemia occurs in 13% of patients. Early recognition of signs and symptoms including nausea, vomiting, lethargy and confusion is essential to initiate prompt intervention including IV fluids, bisphosphonates and steroids. The gastrointestinal symptom can be mistakenly attributed to the underlying disease, cytotoxic or radiation therapy. Hypercalcemia is reversible with appropriate treatment and its progression can often be prevented. However, left untreated hypercalcemia leads to renal failure, progression of neurological symptoms, cardiac arrest or coma.

**Anaemia**

Anaemia occurs in 80% of patients. Symptoms include fatigue, weakness and dyspnea. Prompt treatment is important to improve patients’QOL. Treatment includes blood transfusions and treatment of myeloma. Erythropoietin is given to patients whose anaemia persists after starting treatment.

**Infections**

Recurrent infections are common. Many patients die as a result of bacterial infections. Therefore patient education, prompt recognition of infection and immediate intervention is essential. Patients receive prophylactic antibiotics where the treatment regime is considered high risk e.g. ASCT. Vaccinations for influenza and pneumonia are recommended. Herpes Zoster is common and requires antiviral therapy. Finally, patients with hypogammaglobulinemia and recurrent infections benefit from monthly IV immunoglobulin.

**Diagnosis and treatment**

The diagnosis of MM is based on the demonstration of a M protein in serum or urine and/or lytic lesions by radiography, and the presence of more than 10% plasma cells in the BM. Diagnostic investigations are outlined in (Table 1). 1-2% of patients will have ‘non secretory myeloma’, whereby no M protein is detected.

Patients with asymptomatic disease require no treatment and are monitored for disease progression. Eradication of myeloma is rare. However the availability of effective new drugs to treat myeloma has
significantly extended survival and QOL. The goals of myeloma treatment are: a) facilitate fast control of the disease and reverse any myeloma-related complications (CRAB) b) well tolerated treatment, minimal side effects; c) decrease the risk of early morbidity; and d) allow successful harvesting of stem cells when autologous stem cell transplant (ASCT) is a treatment option 11.

Patients are divided into 2 groups at diagnosis: 1) those < 65-70 years and who are eligible for ASCT and 2) those who are elderly/medically compromised and unsuitable for ASCT.

In the transplant eligible population, randomised trials have demonstrated improved outcomes with the use of maintenance therapy with thalidomide, and, more recently, the use of induction therapy that includes novel agents, particularly bortezomib 13. Treatment choice is influenced by several factors including oral versus IV therapy, renal impairment and risk factors e.g. thromboembolism.

Table 2 outlines the drugs commonly used in MM and their associated side effects. Bortezomib and thalidomide are associated with peripheral neuropathy, careful assessment is required and treatment includes dose reduction and pain control. Thalidomide and lenalidomide increase thromboembolism risk, patients require prophylaxis unless contraindicated 14. Due to the potential teratogenicity of these drugs patient are educated regarding contraceptive advice and avoiding pregnancy, risk management programmes are in place.

Following induction therapy haematopoietic stem cells are collected, the patient receives high dose melphalan and ASCT, mortality risk is 1%. ASCT is not curative, median duration of response is 2 years 7. Patients with complete response (CR) and very good partial response (VGPR) require close follow up. However if CR/VGPR is not achieved a second ASCT or maintenance therapy until progression may be of benefit 3.

For patients ineligible for transplant, the addition of novel agents to the former melphlan and prednisolone (MP) regimen has produced higher remission rates, longer progression free survival (PFS) and, in some trials, longer overall survival. This approach does increase the risk of toxicities. Lenalidomide and weekly dexamethasone is a well tolerated alternative regime. Both strategies induce remissions in approximately 70% of patients 11.

Relapsed/ refractory myeloma

In the majority of patients, MM will relapse. Re-treatment is individualised based on age, presence of comorbidities, previous therapy, quality and duration of response and toxicities and tolerance to therapy. Unfortunately, the duration of response to treatment tends to decrease with each successive relapse.

Bisphosphonates

Bisphosphonates given monthly IV are efficacious for treatment of bone disease. Monitoring of creatinine level pre bisphosphonate therapy is essential and dose reduced where indicated to preserve renal function. Osteonecrosis of the jaw (ONJ) is a complication associated with bisphosphonates characterised by exposed bone within the oral cavity. Dental assessment and treatment is completed pre bisphosphonate where possible. ONJ guidelines have been developed to promote prevention, early detection and minimise the effects of ONJ.

Supportive care/ lived experience

Supportive care is an important component of MM management, provided concurrently with treatment. Transfusion support, G-CSF and erythropoietin therapies have lead to improved QOL and prolonged survival. Unrelieved pain is recognised to be a source of distress and psychological symptoms 11. Nurses have a key role in pain assessment and evaluation of interventions including; analgesia, radiotherapy and bisphosphonates. Early collaboration with palliative care is essential.

Studies on the lived experience of myeloma highlight patient’s challenges includes, living with an “unknown cancer”, isolation and fear of recurrence 12. In response an annual National Myeloma week in June raises awareness and understanding of this incurable cancer. In addition, support is available from www. mymyeloma.ie (dedicated patient website), support groups, Irish Cancer Society and Myeloma UK.
Conclusion

Myeloma remains a complex disease to diagnose and treat. Education about the potential complications of MM and early intervention is fundamental to patient outcome. Treatment options have significantly improved over the past decade along with supportive therapies resulting in improved QOL and survival. Nurses must remain abreast of new developments in order to promote excellence in care.

References

Maxwell C. Role of the nurse in preserving patients’ independence. European Journal Oncology Nursing 2007;

Figure 1. An antibody molecule.
(Courtesy of The Binding Site Group Ltd, Birmingham, UK.)
Or Figure 2
Immunoglobulin structure

Or Figure 2
Bone lytic lesions

Table 2
Treatment options for Myeloma and common side effect profile

<table>
<thead>
<tr>
<th>Peripheral bloods</th>
<th>Skeletal survey</th>
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<tbody>
<tr>
<td>- Full blood count (FBC) / Blood film</td>
<td>For total protein and Bence Jones Protein (BJP)</td>
</tr>
<tr>
<td>- Full biochemistry (including urea &amp; creatinine, calcium and LDH)</td>
<td>Immunofixation</td>
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<tr>
<td>- ESR</td>
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<tr>
<td>- Serum protein electrophoresis and quantitative</td>
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<td>immunoglobulin</td>
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<td>- Beta 2microglobulin</td>
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<td>- Serum free light chain assay</td>
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<td>- C reactive protein</td>
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<tr>
<td>Radiology</td>
<td>24 hour urine collection</td>
</tr>
<tr>
<td>Bone marrow</td>
<td>For total protein and Bence Jones Protein (BJP)</td>
</tr>
<tr>
<td>- Aspirate / Biopsy /Cytogenetics (where available) /</td>
<td>Immunofixation</td>
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<tr>
<td>Fluorescent in situ Hybridization (FISH)</td>
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<tr>
<td>Selected others</td>
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<tr>
<td>- Solitary lytic lesion biopsy</td>
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<tr>
<td>- Plasma viscosity</td>
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<tr>
<td>- MRI</td>
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<tr>
<td>- Abdominal fat/rectal biopsy if amyloidosis suspected.</td>
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Table 2
Treatment options for Myeloma and common side effect profile

<table>
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<tr>
<th>Melphalan</th>
<th>Steroids</th>
<th>Thalidomide</th>
<th>Bortezomib</th>
<th>Lenalidomide</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lower resistance to infection</td>
<td>Increased risk of infection</td>
<td>Peripheral neuropathy</td>
<td>Peripheral neuropathy</td>
<td>Myelosuppression</td>
</tr>
<tr>
<td>Bruising/bleed</td>
<td>Irritation of stomach lining</td>
<td>Constipation</td>
<td>Gastric disturbances</td>
<td>Constipation</td>
</tr>
<tr>
<td>Anaemia</td>
<td>Steroid induced diabetes</td>
<td>Risk of thrombosis</td>
<td>Thrombocytopenia</td>
<td>Risk of thrombosis</td>
</tr>
<tr>
<td>Nausea</td>
<td>Fluid retention</td>
<td>Rash</td>
<td>Low blood pressure</td>
<td>Thrombocytopenia, neutropenia</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Increased appetite</td>
<td>Fatigue</td>
<td>Fatigue</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Behavioural changes e.g. low mood</td>
<td></td>
<td>Birth defects</td>
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Multiple Myeloma:
Nurses to play key role in novel trial network

By Maggie Lai, Myeloma UK

Background

We have recognised for a long time that the process of developing and accessing new life-prolonging treatments for myeloma is unacceptably slow and ineffectual. As a result, patients directly suffer because these drugs are either not being developed quickly enough, are not appropriate or are not made available on the NHS.

This is partly because there has been no formal national approach to early phase trials, studies take too long to set up and complete because of administrative hold-ups and there is no clear strategy linking the crucial steps from early to late phase studies.

As one of several ways to overcome these challenges, Myeloma UK has recently set up and is funding a first of its kind Early Phase Clinical Trial Network to transform the way treatments for myeloma are being tested and accessed in the UK. The first trial is expected to open at the end of 2010.

By bringing together the very people who can address these challenges - researchers, doctors, nurses, the pharmaceutical industry and the NHS - our collaborative network is changing the landscape of myeloma clinical trials in the UK.

Excellent progress has been made in establishing the infrastructure of the Network. In May 2010, following competitive tendering processes, we confirmed the appointment of the University of Leeds Clinical Trial Research Unit to be the Network Clinical Trial Coordinating Office (CTCO) and appointed eight Active Trial Centres (ATCs) across the country to conduct the trials.

All of the ATCs are well established tertiary centres (Table 1) each with their own network of collaborating local hospitals. In the near future we will be taking a strategic approach to incorporate more trial centres into the Network to enable even more patients to access myeloma trials.

As part of the network approach, we have identified and are beginning to directly address the bottlenecks that are currently delaying the set up and delivery of early phase trials. Recruitment of critical core trial staff including research nurses, trial coordinators and data managers in each of the ATCs has begun.

Within the next two years we aim to have established a fully-resourced, effective and streamlined network delivering a portfolio of prioritised early phase trials in myeloma, allowing patients to gain access to the best possible novel treatments at the earliest opportunity.

The portfolio of trials will be targeting two key areas of research: Phase I / II studies of novel molecules / pathways either as single agent therapy or in combination with conventional treatments, and Phase II studies either to inform Phase III studies or to complement registration studies to address currently unanswered clinical questions in myeloma.

Nurses role in clinical trials

Nurses at all levels can play an increasingly important role in the clinical trial setting. Nurses are taking greater responsibility in coordinating trials, assisting with protocol development and set-up as well as providing the more traditional role of patient education and advocacy of specific trials to facilitate accrual. Very often it is the nurse to whom the patients turn to for further information about trials and for follow-up. This role should not be confined to research nurses but all nurses have a responsibility to develop the skills and knowledge not only to inform patients of available trials but also be involved in the continuing educational process throughout the trial e.g. in managing symptoms and side-effects and patients’ expectations of trial outcomes.
Nurses role in the Network

Myeloma UK recognises that the education of nurses is a key aspect of delivering high quality nursing care to myeloma patients. Since 2002 we have promoted nursing education primarily through our Myeloma Nurse Programme which includes the recently launched updated online Myeloma Nurse Learning Programme©.

The involvement of nurses, not just those employed in the Network, but also those in the wider ATC referral regions, will offer an additional educational resource by bringing them up to speed with the current understanding and the latest cutting-edge technologies in diagnosis and treatment of myeloma.

Within the Network, nurses will be able to develop and share best practice and training ideas, and share experiences of the challenges of the clinical trial environment and how best to overcome them. Each year, we will bring nurses together for Network education days.

How nurses can get involved

The Active Trial Centres are currently recruiting experienced research nurses to assist with the running of the portfolio of trials. Nurses working in collaborating centres can get involved by contacting the ATCs for information of each trial as they come through.

Whether nurses are working within one of the eight ATCs or their collaborating centres, or in other hospitals, Myeloma UK is extending an invitation to all nurses to help raise awareness of the Network and its trial portfolio. To find out more, contact Maggie Lai at Myeloma UK: Maggie@myeloma.org.uk

About Myeloma UK

Myeloma UK provides information and support to people affected by myeloma and aims to improve treatment and standards of care through: education; research; campaigning and raising awareness.

Myeloma UK is the only organisation in the UK dealing exclusively with myeloma and its related disorders. For more details of all Myeloma UK programmes and services, visit www.myeloma.org.uk

Myeloma UK works closely with nurses through its pioneering Myeloma Nurse Programme providing practical and educational resources to nurses with an interest in myeloma. The programme is dedicated to developing the role of nurses to help raise awareness of myeloma and to optimise the information, support and care delivered to myeloma patients, their families and carers.

The latest addition to the programme is the innovative online Myeloma Nurse Learning Programme, an unparalleled, flexible self-learning educational tool endorsed by EBMT and EONS and credit-rated by Edinburgh Napier University. To find out more or to enrol, visit www.magicfornurses.co.uk or contact lois@myeloma.org.uk
On the 10th of September I was invited to visit the Emergency University Hospital in Bucharest.

Dr. Horia Bumbea (Haematologist) at the Emergency University Hospital in Bucharest gave me a full tour of the hospital. Visiting and meeting our colleagues in the Hospital was a very interesting and educative experience for me. Dr. Bumbea showed me the inpatient ward with 25 beds for haematology patients, as well as the outpatient clinic.

One of the goals of the EBMT Nurses Group is to support educational events and to make them accessible for all the nurses and other health care professionals.

During my visit in Bucharest I had meetings with nurses, haematologists and a representative of the ministry from Romania to discuss several possibilities to educate our colleagues working in the field of haematology and haematopoietic stem cell transplantation in Romania. At this time we are still talking about organizing a study day in Romania in 2011 for nurses and other health care professionals. We will inform you about this upcoming event as soon as we have more details.

On the 11th of September I was invited to present during the “1st Myeloma Euronet Romania Patient and Family Day” to represent the EBMT Nurses Group and talk about the role of nurses in blood cancers. This was an opportunity to showcase the work of the EBMT Nurses Group and to present the role of haematology nurses and other health care professionals and to communicate with patients and their families in Romania.

For more details please contact Erik Aerts at erik.aerts@usz.ch
I have been asked to write a brief overview of The Christie complementary therapy service for the EBMT NG newsletter. I am very grateful for the opportunity to describe what we do as I hope this will also prove to be the beginning of a supportive network or forum for nurses using (or wanting to use) complementary therapies in haematology throughout Europe.

Since 1997 we have gradually been increasing our services at The Christie so that in 2009 we offered massage, reflexology, aromatherapy & relaxation to 7,300+ patients, 1,000 plus carers 1,500 staff. Whilst this is a trust wide statistic, the haematology transplant unit is one of the main users of the service. Examples of some of our more recently introduced therapies (since 2005) and indications for use can be seen below:

**Acupuncture:**
hot flushes, fatigue, peripheral neuropathy, pain and insomnia

**Hypnotherapy:**
assisting patients cope with needle phobia, needle anxiety and anticipatory nausea

**Clinical use of essential oils:**
wound care, scleroderma

In addition to working alongside clinicians and other health professionals to help manage patients with complex physiological and / or psychological needs, I initiate and lead research relating to the use of complementary therapies in the clinical environment including collaborative work with businesses and other healthcare institutions.

Our work at The Christie has developed to such an extent that it is seen as a service integral rather than additional to the care of the patients. Having observed the benefits of our work in Manchester, it would be wonderful to be able to support other nurses across Europe to develop similar services within their own centres. I am aware however that challenges to such a venture maybe different in Europe to those faced by nurses in the UK. Equally, therapies used in Europe may differ from the ones listed here. In order for such a vision to move forward therefore I would like to appeal to any nurses who have experience of setting up a successful complementary therapy service in their own place of work who would be interested in / prepared to, support others either directly or indirectly to contact me. Equally, in order for me to clarify whether such a forum would be useful or in what format it would be most helpful, I would welcome comments from any members. My ‘blue sky vision’ would be to develop our work in this field to a place where we could produce European guidelines for practice and develop collaborative research projects. I look forward to hearing from you!

**Journal Papers /Chapter (last 5 years)**


Educational Initiatives

The Skeletal Care Academy (SCA) is an education programme developed to ensure that patients with cancer-related bone disease receive the highest standard of multi-professional care, allowing them to enjoy fuller, healthier lives.

The SCA gave a presentation at last year’s EBMT conference in Vienna.


A similar SCA event is planned for 25-26th February 2011 and as soon as we have more details we will inform you.

EBMT NG Paediatric Sub Committee Update
The 2nd Meeting of the EBMT Paediatric Nurses 2-4 June 2010 in Helsinki, Finland

We had a successful Paediatric Nurses meeting in Helsinki, Finland. There were 33 nurses from different European countries and also nurses as far as Chile and Japan. During the 3 day meeting we had both nurses’ presentations and joint sessions with physicians.

The nurses presentations were about: mixed wards (adult and children), sexuality, school in hospital, CVC-complications, adverse events of ATG, SCT complications with thalassemia major, fatigue in bmt children, parents staying overnight in hospital, reporting errors and also presentation about the Nordic nurses cooperation. Joint sessions covered controversies in indications, regulations and processes, GvHD, infectious issues and supportive care and also late effects. There was also a social programme where participants could share experiences and ideas in the long lasting northern light.

We believe that everyone made many new contacts and discussions during breaks were enthusiastic. Let’s keep on bonding with other paediatric nurses.

We hope that all paediatric nurses are active and are sending abstract for review in the forthcoming meeting in Paris.

On behalf of the EBMT Nurses Group Paediatric Committee I want to thank all the participants for their input.

Merja Stenvall
Local Nurse
Merja.stenvall@hus.fi

Members of the NG Paediatric Sub Committee with Joachim Blankart, EBMT NG Board Treasurer during the meeting in Helsinki.
EBMT NG Dutch National Group

The Dutch national SCT nurses group has transformed into the Dutch national haematology nurses group in October 2009. Members of this nurses group are from all over the country and have their work activities in different fields. Members can work on clinical or outpatient SCT and/or hemato-oncology wards, and some of our members are for example paediatric nurse or nurse practitioner.

Because of this very large range and different patient groups, we had the aim at the start to map out clinical pathways of the treatment of leukaemia in children and adults. So we hope to find out what problems both groups have in common. Until now we did not succeed to complete these pathways but hope we’ll do this year.

We think it’s necessary to make an inventory of these similar problems to reach more cooperation between the nurses treating adults, paediatric nurses and nurse practitioners: we’re looking for similar goals to deal with.

In spite of this intern transformation which takes a lot of our time, we have two sessions at the yearly oncology congress of the Dutch oncology nursing society in December 2010. This year we’re organising a lunch meeting and a breakfast meeting. The subjects are: "new developments in haematology care” and “changes Multiple Myeloma and Myelo Dysplastic Syndrome care”.

Marjan Rademaker,
Chair of the EBMT Dutch National Nurses Group
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EBMT NG Spanish National Group

During this year (2010), the Spanish National Group (GEE-TPH) has made important changes, bringing opportunities to expand and include as board members nurses from all Spanish Communities. In order to properly organise the elections, several changes in the Constitution and Statutes of the Group were necessary. So, we redefined parts of it and made the changes available to all the Spanish NG members by E-mail and in the National Group section of the EBMT NG website. It was important to ensure that all our existing members agreed with the proposed changes.

The General National Meeting took place at the end of The 4th National Study Day (Valencia, May 2010) where all the proposed changes in the Statutes were approved, which meant the election process could start.

The two new vacancies were President Elect and Treasurer. At the end of one of our regular meetings it was revealed that Eugenia Trigoso is our new President Elect (Hospital La Fe, Valencia) and our new Treasurer is Julia Ruiz (Hospital Niño Jesus, Madrid). We welcome them both, we are sure that these incorporations will come with new opportunities, ideas and development in the area of TPH. Also, from their curriculum and background we know that they will be very instrumental in leading the group forward to face new challenges during the coming years. We would like to thank Asunción Turro and Montserrat Valverde for their helpful involvement and collaboration since the EBMT Spanish NG started back in 2006. It will be a pleasure to keep them working and attached to the group from a different standpoint.

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Last May we held The 4th National Study Day in Valencia together with the Physicians Group (GETH). Now we are preparing the 5th National Study Day and National Meeting, which will be organised for March 10th and 11th in Madrid with the support of the GETH. Also we hope that by then we will be able to organise the second part of our board member changes and have everything ready so that members can vote for the Secretary and President Elect.

Information about the next general elections and proposed content of the Study Day will be available soon in the following web page: www.ebmt.org/6NursesGroup/nurses9es.htm

Núria Borràs
Secretary of the EBMT- Spanish Nurses Group
GEE-TPH

Cristina Gallego
President of the EBMT – Spanish Nurses Group
GEE-TPH

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**EBMT NG UK National Group Update**

*You can download the article here:*
Important Dates and Upcoming Meetings

04 Dec – 07 Dec 2010
52nd ASH Annual meeting and exposition
Orlando, Florida

16 Dec – 17 Dec 2010
Dutch Oncology Nursing Society
http://www.oncologie.venvn.nl/
Deskundigheidsbevordering/Oncologiedagen.aspx

10 Feb 2011
Heamatology and Transplant Nurses Conference
Manchester, UK
peter.nield@cmft.nhs.uk

25-26 Feb 2011
Skeletal Care Academy
Madrid, Spain
www.skeletalcareacademy.com

2 April 2011
5th EBMT Patient & Family Day

3-6 April 2011
27th Meeting of the EBMT Nurses Group
Paris, France
http://www.congrex.ch/ebmt2011/

23 - 27 September 2011
Joint ECCO 16 - 36th ESMO Multidisciplinary Congress
Stockholm, Sweden
http://www.ecco-org.eu/Conferences-and-Events/
Calendar-of-events/page.aspx/170

05 Nov 2011
2nd EBMT Joint Nurses’ Group and Lymphoma Working Party Study Day
Zürich, Switzerland

27 September – 1 October 2013
Joint ECCO 17 - 38th ESMO Multidisciplinary Congress
Amsterdam, The Netherlands
http://www.ecco-org.eu/Conferences-and-Events/
Calendar-of-events/page.aspx/170

A regularly updated list of all meetings and conferences taking place can be found here:
http://www.ebmt.org/2RelatedMeetings/annual2.html

Specific EBMT meetings and study day details can be found here:
http://www.ebmt.org/EBMTmeetings.html

Various courses taking place in Switzerland can be found in the following website:
http://www.onkologiepflege.ch/Fortbildungen.fortbildung0.0.html

Worldwide Haematology Congress details. Click here: