



March 2009

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EBMT NG Presidents Introduction



The EBMT Nurses Group is looking back upon an intensive and successful year and herewith I would like to start, by thanking all the members of the EBMT Nurses Group; the members from the several committees and colleagues from the Nurses Group and EBMT Board for all their hard work and support during the last year!

In this edition of the Newsletter you will find contributions from the various committees and colleagues.

In 2008 the members of the EBMT Nurses Group joined several meetings in Europe; you will find the experiences of the colleagues who joined those meetings in this newsletter.

We have also contributed to various meetings together with representatives from patients' associations from different countries from Europe. What was so special about these meetings was being able to recognise how specialised these patients advocates are. Also, another important aspect of these meetings was the importance that nurses, allied health professionals, physicians and patients should work more collaboratively to develop the care for our patients.

Milestones and Special Events...

In November one of our members attended a meeting with the Late Effects Working Party, where we discussed the involvement and collaboration of the EBMT NG within this Working Party.

The 8 National Groups are working on several projects in a regional, national and international scale. The expansion to different countries is one of the goals of the EBMT NG Board. At this moment we are in talks with our colleagues in France and Turkey to set up a national EBMT NG.

We attended several meetings with the national groups in Germany and Switzerland and on the 21st and 22nd November we joined the Nordic BMT Forum, where we represented the EBMT NG and discussed joining the EBMT Nurses Group as a Forum with our colleagues from the 5 Scandinavian countries.

In December the NG Board had a one-day board meeting in Göteborg and afterwards the members of

the Scientific Committee worked on the preparation for the Meeting in Göteborg.

A New Sub Committee...

On the 7th September 2008 the EBMT NG Board agreed and decided to set up an NG Paediatric Nurses Committee within the EBMT Nurses Group. In December suitable candidates were selected and I would like to welcome and introduce you to the following members of this recently formed committee; Eugenia Trigo (Valencia, Spain) and Mr. Marco Deiana (Genova, Italy).

Discussions regarding projects to start work on with the new members of the Paediatric Committee have already begun and we hope to provide you with more news soon.

Educational Initiatives

The EBMT NG Board feels it is important to expand and optimise existing educational projects accessible to haematology nurses across Europe. At this time we are in contact with several groups and companies to plan those educational projects and we will update you about those initiatives as soon as we have signed off our agreements.

25th Meeting of the EBMT Nurses Group

The members of the Scientific Committee have composed a very interesting and special program for this special 25th Meeting; you can already get to know part of this in the conference web site: www.congrex.ch/ebmt2009/

The opening Session on Monday 30th March will be a plenary where we will celebrate our 25th Anniversary.

At the end of the Session, a colleague who has been working in the field of SCT will receive the 1st EBMT-NG Distinguished Merit Award.

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EBMT NG Presidents Introduction (cont...)

We are also very pleased to announce that we can award a 1st, 2nd and 3rd prize for best abstracts/oral presentations sponsored by Fresenius Biotech, and one prize for the best poster sponsored by Novartis Oncology.

National Nurses Groups and Forums will have the opportunity to meet and discuss national matters of SCT Nursing interests and countries that do not have a formal national group yet will be encouraged to get together and discuss setting up a national group. To do this we will use information flyers to point out where

colleagues from the different countries are in order to optimise contact and assist networking.

Our hope is that while attending the next Annual Meeting you will obtain inspiration and ideas, which you can take back with you to share at your workplace.

On behalf of the EBMT Nurses Group Board, we are looking forward to welcoming you in Göteborg!

Yours faithfully,

Erik Aerts

President of the EBMT Nurses Group

Communication & Networking Committee

A very Happy and Healthy New Year to you all

In September 2008 we asked you for feedback on the EBMT Nurses Group Newsletter. We wish to thank the 51 members who participated in the survey.

The results are very positive and helpful: 80% read the Newsletter electronically, so the Email format is well accepted. 62% forwarded the Newsletter to colleagues and some of them to up to five persons.

The new layout was enjoyed by 87% of the participants and 81% rated the information quality as high. Important dates and upcoming meetings is the most read section, but also the other sections are rated as interesting, easy to find and clearly written. We received suggestions to include more paediatric themes and one medical topic in each issue e.g. the latest news from a working party, a JACIE section or more practical nursing information.

The Communication and Networking Committee is very grateful for your feedback. We plan to discuss your suggestions at our next meeting in Goteborg and probably you will find new themes in the future. Thanks again and if you have any ideas or questions don't hesitate to contact us.

The GVHD educational DVD that the EBMT-NG Research Committee completed last year can now be accessed from the main page of the EBMT-NG website: www.ebmt.org/6NursesGroup/nurses1.html.

The DVD has been developed to provide healthcare professionals with a better understanding of the disease and to help them educate and support patients

and carers. The DVD uses the latest research findings, the expertise of healthcare professionals and the views of patients to address the pathophysiology, treatment and care of GVHD.

The 25th Meeting of the EBMT Nurses Group is just around the corner and the Scientific Committee have put together a very full programme with many interesting sessions which you can read about in their update.

In this Issue you can find a summary of last years EBMT 2008 workshop about Skin Care & Graft versus Host Disease. Roel de Weijer has summarized his presentation to make it accessible to every member.

Finally we would like to thank everybody who contributed to this issue of the Newsletter!

Kind regards,

Sara Zulu

zulu@lumc.nl



CNC team together at EBMT 2008, Florence, Italy. From left to right: Sara Zulu, Sabine Degen and Amélia Muerst

News from the Board

Changing Nature of the CML Journey

Arno Mank

President Elect EBMT-NG

The CML journey has changed dramatically; as a result novel approaches to the management of CML including the introduction of new drugs mean patients are now living longer and able to live quite a normal lifestyle. More and more patients are being cared for in an ambulatory care setting where they have limited opportunities for interaction with other patients and health professionals. For this reason a CML Patient and Nurse Advisory Meeting was held in Zurich Switzerland on November 10 and 11 in 2008. This meeting was organised by Novartis in cooperation with the EBMT-NG. Novartis invited 7 patient advocates and 6 experienced haematology nurses to attend. There were separate meetings with the advocates and nurses and then the patient advocates and nurses met together. The following subjects were discussed during those 2 inspiring days:

Challenges for patients transitioning from one oral CML therapy to another

Most patients do not appear to have had difficulty transitioning from one medication to another. The administration schedule and physical consequences of these new drugs is of course an important issue for discussion. The medication treatment options and developing resistance was another topic discussed between the patient advocates.

Barriers to meeting the informational needs of patients with CML

The value of educating patients in general is often underestimated. Lack of time is a key issue in the ambulatory care setting where most patients with CML are now seen. Physicians have a limited amount of time to spend with each patient and many patients are never seen by a nurse. Unlike with other chronic conditions, there are few clinical nurse specialists for CML who could help meet patients informational needs and promote treatment adherence. The potential of patient groups as a source of information and support should be used more often and too few health professionals

refer new patients to patient groups. Some European patient groups have managed to reach more patients by involving health professionals in their organisation as either members or advisors.

Strategies for channelling information to patients

All over Europe Many patient groups develop informational resources themselves and distribute these to members written as well information on-line. Factors that contribute to the success of patient group-generated materials are involving key physicians and nurses in the development and checking of content and securing agreement from clinics and physicians to distribute materials. Key to the success of this approach is to ensure that the display with patient material is highly visible and that someone takes responsibility for replacing stock. Other useful suggestions from the patient advocates were to have a patient volunteer in the ambulatory care to provide support and information for other patients and to have a list of questions to ask their doctor about their disease and its treatment.

Promoting medicines adherence in CML

People living with CML want to live as normal a life as possible and consequently every effort should be made to ensure that adherence promoting strategies help achieve this goal. Although non-adherence is a multi-faceted and complex phenomenon, health professionals are very aware of the impact of non-adherence in the CML setting but are not aware of the scope of the problem and what they can do to promote medicines adherence. The most important way to promote adherence to oral CML medicines is by talking to patients and providing adequate explanation about their medicines. A specialist nurse could run a regular adherence consultation for groups of patients. In different European countries are initiatives for reminder devices such as SMS reminders and other timers A number of different types of patient materials have

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News from the Board (cont...)

been developed such as: Informational leaflets, Dial-a-dose wheel, Dosing pads and pharmacokinetic schematics.

Meeting nurses' educational needs about CML and adherence

There are significant gaps in nurses' knowledge about CML and recent treatment advances especially outside of the specialist setting. There is value in developing a

pan-European nurse education initiative on CML or to broaden the topic to chronic leukaemia's since there are many commonalities across these diseases, especially from a nursing management perspective. Non-adherence should be an important component of this educational initiative. It would be valuable to include patient advocates in developing the curriculum and content. Novartis and the EBMT-NG are now exploring the possibility of moving this initiative forward.

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“CML Advocates Network” joins forces of leukaemia advocacy groups worldwide



Patient groups representing rare cancers like leukaemia greatly benefit from sharing knowledge and collaborating across borders. The CML Advocates Network, founded in 2007, is both a virtual network and an internet platform connecting 34 leukaemia patient groups from 28 countries.

The main objectives of the “CML Advocates Network” are:

- To provide a public web directory of CML patient groups worldwide, to allow patients to find national support groups in another country.
- To provide a platform for communication, education and knowledge sharing between CML patient advocates
- To coordinate joint activities and advocacy work.

The network is solely run by patient groups on a low-cost basis, and is maintained without government or industry support. This ensures its financial independence from commercial or political interests.

At a worldwide meeting of CML Groups in June 2008, more than 50 delegates from organisations representing patients with chronic myeloid leukaemia (CML) signed the “Baveno CML Declaration”. The declaration calls for improved access to cancer treatment, better adherence to internationally agreed treatment recommendations for CML, and equal access to up to date

treatment from multidisciplinary teams in all countries. In 2005 and 2006 the global CML community proved its effectiveness by a successful letter writing campaign which called upon politicians in Poland and Hungary to improve patient access to leukaemia treatments approved in the EU.

“Our goal is to help leukaemia patient groups work together across borders. Many organisations face similar challenges, but have different levels of experience and varying national and local health care systems. The network helps us to learn from each other and to coordinate our advocacy initiatives”, said Jan Geissler, president of Leukämie-Online and director of the European Cancer Patient Coalition (ECPC). “The CML Advocates Network has been very well received by CML groups worldwide”, said Sandy Craine, founder and trustee of The CML Support Group UK and secretary of ECPC.

In November 2008, representatives of CML patient groups and specialist oncology nurses attended a meeting in Zürich to discuss issues around improving patient compliance with cancer therapy. “In many countries nurses have a key role in providing expert care and information to leukaemia patients. We are delighted to discuss with EBMT ways in which nurses and patient advocacy groups might work together more effectively in order to improve the treatment and care of leukaemia patients” Jan added.

Jana Pelouchova, director of the Czech CML patient group “Diagnoza CML”, stressed the importance of specialist support nurses in directing patients to their local and national patient support groups. “We can improve the outcome of therapy by working together. This can improve levels of understanding of both the disease and therapy. This will inevitably improve both compliance and consequently treatment outcomes” she said.

CML Advocates Network
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Leukämie-Online e.V. (Germany)
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Jan Geissler
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CML Support UK
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Diagnoza CML (Czech Republic)
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GvHD Skin Care Interventions

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Last year at the EBMT congress we had a workshop titled 'skincare after SCT'. Here, I would like to provide a summary and conclusion of the workshop.

GvHD is the most common complication after stem cell transplantations (Socie et al 1999, Vogelsang et al 2004); there are many studies done about GvHD, but none of the studies give the answer to 'how to treat GvHD' (Gaziev et al (2001). Most of the studies are medical and a few are from other disciplines. Most literature currently used by nurses are based on descriptions of a particular case.

One of the objectives of the workshop was to talk with other nurses in Europe about what they are doing for patients with GvHD. After an introduction and some questions we discussed things in small groups and later on in the whole group. There were a lot of interventions mentioned, most of these being medical, which amazed me as I assumed most interventions would be based on the nursing care as it's the nurses who mostly deal with GvHD patients.

We all know that the medical treatment is not the only patient solution. We can treat patients for their GvHD, but a lot of them (more than 40%) do not respond to the treatment (Akpek et al 2002). So, what can we do as nurses for these patients? In this particular workshop we concentrated on skincare. Beside the medical treatment it was hardly mentioned what we as nurses do and what kind of advice we can provide. But, here are some interventions we all seem to be aware of and actively execute:

- We all advise patients to use an oil based cream/lotion to care for their skin. Every country had its own particular brand it used but this was difficult to compare. In reality we don't really know if its better to hydrate/moisturise skin before or after using the oil based cream/lotion. It seems logical to moisturise the skin but we concluded that as there is no evidence, we have to work with interventions based on experience.
- There is a difference between the south and the north of Europe. We all give the advice to the patients to protect their skin from sunlight using a cream with an SPF of 20 and to wear clothes. But in the south of Europe they also advise patients to protect their skin when inside by closing curtains and using sun

screens. We all appear to advise the patient to wear clothes made from natural fibres (linen, cotton or silk).

- None of the nurses we spoke to were familiar with massage techniques for the skin or suitable exercises.

I think its safe to say that we can support a better quality of life for a GvHD patient if we know how to provide a skin massage – the skin may stay in a better condition. In the literature available you can read that massage of the skin can help the patient, but they don't describe how to do it (Vogelsang 2001). Even so, I think it would be better for the patients if they are doing some exercise for their joints in the places where there is some GvHD on the skin. If they do the exercise the joints will be moving and the skin will be slightly less stiff - it will be better for the skin, but also for the joints. If the skin is stiffened, patients prefer not to move too much because it is inconvenient. And later on they can not move at all because the joint is so stiff it can get locked.

My conclusion from the workshop is that all nurses wanted to have interventions for their GvHD patients, but there are no evidence based interventions. Thus, it is hard to know what to do.

I believe the start for better interventions will be to tell each other about what you are doing and why, together we can become of more interventions which we can adopt in our workplaces. We should discuss this problem in our own department/ hospital, national groups or international groups such as the EBMT.

I hope you can make contact with other colleagues and discuss your problem. Together we can do it!!

- 1 Akpek, G. (2002) Clinical Grading in Chronic graft-Versus-Host Disease: Is it Time for Change?: Leukemia and Lymphoma: Vol 43, No 6, 1211-1220.
- 2 Gaziev, D. Lucarelli, G. (2001). Novel approaches to the treatment of chronic graft-versus-host disease: Expert opinion on investigational drugs: Vol.10, No 5, 909-923.
- 3 Socie, G. Mary, J. Esperou, H. et al (2001). Health and functional status of adult recipient 1 year after allogeneic haematopoietic stem cell transplantation: British Journal of Haematology: Vol 113, 194-201
- 4 Vogelsang, G.B. (2001). How I treat chronic graft-versus-host disease: Blood: Vol 74, 1196-1201.
- 5 Vogelsang, G.B. Hignman, M.A. (2004). Chronic graft versus host disease. British Journal of Haematology: Vol 125, 435-454

Local Nurse Diary – EBMT 2009

Elisabeth Wallhult, Inger Andersson and Joacim Larsen,

Local Nurses for EBMT 2009

This is the last report before the meeting in Gothenburg and the expectations and temperature is rising - we are really looking forward to meeting you all in March.

But there is still work to be done, in December the NG Scientific Committee met during the weekend in Gothenburg for the abstract selection. A total of 162 abstracts (we know then that at least 162 nurses will attend the meeting!!) were sorted out for oral and poster presentation. It was really hard work and Inger and Joacim were glad to have some experience from attending the abstract selection meeting in Florence last year. As local nurses we had to read all of the abstracts, and that, we can say, took some time...

At this meeting we also met the local nurse for the next meeting in Austria 2010. We tried to inform her of the work she can look forward to and her responsibility as a local nurse for the meeting. It's important as a local nurse to be involved in the work as soon as possible and the abstract selection is a really good op-

portunity to learn the process and to get to know the persons in the scientific committee at an early stage.

The program is now settled and all speakers have been invited and accepted and we can promise you it will be a very interesting and varied program where there may even be some surprises.

We will have two further telephone conferences with the NG Scientific Committee before the meeting, where we will go through everything and see if we have missed anything. There will also be meetings within the local group to ensure that everyone has fulfilled their obligations.

Of course we hope that there will be many nurses attending the meeting in Gothenburg but we also hope you have the time to see something more than the convention centre. Gothenburg is a lovely city and besides the tours you can read about in the program we can recommend many other places worth seeing.

Looking forward to seeing you all in Gothenburg!

EBMT NG Scientific Sub Committee Conference Update

Mairead Ni Chonghaile,

St. James's Hospital, Dublin, Ireland - Chair, NG Scientific Sub Committee

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Well that time of year has come around again – it is hard to believe that nearly a year has passed since the meeting in Florence. This year sees the 25th meeting of the EBMT Nurses's Group (NG) – a significant milestone for any group. In December the scientific committee met in Göteborg and finalised the programme for the meeting. We had 171 abstracts submitted for consideration from which we selected the candidates for oral and poster presentations.

The conference will start on Sunday 29th March with the study day aimed at nurses and health professionals who are less experienced and new to the field of transplantation. The focus of the 5th Annual Study

Day will be "Donor Issues" in the morning and "Infectious Issues" in the afternoon.

For the more experienced nurse and allied health professional, the Nurses group is pleased to announce a new departure with the introduction of an afternoon session on Sunday for this group of practitioners. Attendees will be welcome to attend the morning session of the Pre meeting study day or this session only. The focus of this session will be on evidence based practice and vaccination strategies post HSCT.

The meeting will open on Monday with a special plenary session celebrating 25 years of the NG with a focus on the history of HSCT, the NG and its achievements.

Of course we hope that there will be many nurses attending the meeting in Gothenburg but we also hope you have the time to see something more than the convention centre. Gothenburg is a lovely city and be-

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EBMT NG Scientific Sub Committee Conference Update (cont...)

Educational Sessions

As usual we will have 6 educational sessions aimed at giving an insight in diseases and clinical and management issues. The six sessions are:

Day	Session	Speaker
Monday	Total Body Irradiation	M Adams (London UK)
	Chronic Myeloid Leukaemia	J Apperley (London, UK)
Tuesday	Myleodysplastic Syndromes	M Markiewicz (Katowice Poland)
	An overview of regulation & accreditation in HSCT units	D Pamphilon (Bristol, UK)
Wednesday	Reduced Intensity Transplant	M Ni Chonghaile (Dublin Ireland)
	Autoimmune diseases in children	A Fasth (Goteburg Sweden)

Plenary & Workshop Sessions

In a new departure this year the Nurses group will hold 2 workshops which will have limited capacity – registration will be available via your meeting registration form and any available spaces will then be allocated on a first come first serve basis will be in Göteborg. It is hoped that by doing this we will be able to have a more interactive and practical session and each of these sessions will be repeated (one on Tuesday morning and the other on Wednesday morning). The other 4 sessions will be plenary sessions giving participants the opportunity to meet the expert. These sessions will be on Monday.

Type	Session	Proposed Speaker
Workshop (limited numbers & repeated on Tuesday)	Complimentary Therapies	C Wendt (Lund SE) C van Eltink (Amsterdam NL)
Plenary	Palliative care in paediatrics	Marie-José Pulles (NL) Yvonne Hakansson (Lund, SE)
Plenary	GvHD – New therapies, nursing care & Photopheresis	R Weijer (Utrecht, NL)
Plenary	Quality Management	N Som (Bristol UK)
Plenary	Compliance – Whose responsibility?	J Larsen (Stockholm SE) & M Fliedner (Berne CH)

here will also be a plenary session on Tuesday titled “More confidence in stem cell mobilization and collection” looking at developments in this area.

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EBMT NG Scientific Sub Committee Conference Update (cont...)

Joint session

The joint session on Tuesday morning is an exciting opportunity for us to get together with the other disciplines attending the meeting and collaborate. This year is an exciting session looking at Quality of life and the future for our patients. We are excited to have 3 speakers dealing with this topic and the session is as follows:

Quality of Life lessons - Into the future

- 1 Quality of life Studies, the nuts and bolts - Prof A Kiss (Basel, CH)
- 2 The impact of genital GvHD on life - Dr E Smith-Knutsson (Trollhattan, SE)
- 3 The impact of long-term follow up on survivorship - Dr D Greenfield (Sheffield UK)

Prizes

The meeting will have the usual poster and oral presentations and we are pleased to announce that our prizes for best oral presentation will be sponsored again this year by Novartis and the best poster prize will be sponsored by Fresenius.

The meeting will have the usual social events and the poster viewing sessions in the evenings giving us all the opportunity to meet and chat with colleagues and exchange ideas and experiences.

The Scientific Committee looks forward to seeing you in March and wishes you all an enjoyable conference. The final programme will be available towards the end of February at www.akm.ch/ebmt2009

EBMT NG Research Sub Committee Update

Eva Johansson,

Karolinska University Hospital, Stockholm, Sweden - Chair, NG Research Sub Committee
eva.mo.johansson@karolinska.se

The Research Sub Committee (RSC) has the great pleasure to, on behalf of the EBMT-NG, support EBMT-members on issues regarding nursing research and to promote evidence based practice and clinical knowledge. The present members of the RSC are, Eva Johansson (Chair), Sarah Liptrott, Corien Eeltink and Simona Calza. Short biographical sketches to assist getting to know us better were provided in the last issue of the EBMT-NG newsletter.

We are also happy to introduce a newly elected member, his name is Patrick Crombez. He has a Master in science of nursing and is the Head Nurse of the haematology and stem cell transplantation ward at the Jules Bordet Institute in Brussels. For many years he has been involved in clinical research and his special interests are evidence-based symptom management, gero-oncology, and long term post transplant quality of life.

At present, our group the group is working on several interesting projects. In 2007, an educational DVD on GvHD was produced by the EBMT-NG, which was distributed to all EBMT nurse members and to Principal Investigators at EBMT centres without a listed nurse. To elicit the satisfaction and utility of this education resource a web-based questionnaire has been sent by e-mail to all EBMT-NG members. The results from the survey will be presented at the EBMT conference in Göteborg. As part of the 25th anniversary of the EBMT-NG, we will also present an overview of the nursing activity at the EBMT-conferences during past years.

The results from the Research Priority Survey performed in 2007 were presented at the EBMT-conference in Florence 2008. Patient information was found by nurses to be a highly relevant research area in relation to care of patients undergoing stem cell transplantation. The RSC also finds this topic very important, and in particular the written information. As a complement to verbal communication, the written information may for example involve patients in their condition and their treatment, help patients remember - the written information can also be shared with family and friends. At future RSC meetings, we will

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EBMT NG Research Sub Committee Update (cont...)

make plans on how to proceed working with this topic. Examples of questions that have been addressed so far within our group are: What written information is available for patients undergoing stem cell transplantation? Is the available written information comprehensive? And, is the information understandable to patients, family and friends?

We welcome you to discuss these projects with us, and also share other questions you might have, our email addresses can be found at the following website:
www.ebmt.org/6NursesGroup/nurses3.html.

Being a nurse, working in haematology and stem-cell transplantation, your contributions are not only appreciated, they are vital to the continued improvement of the quality of patient care!

EBMT NG National Groups Update

Nordic Forum Update

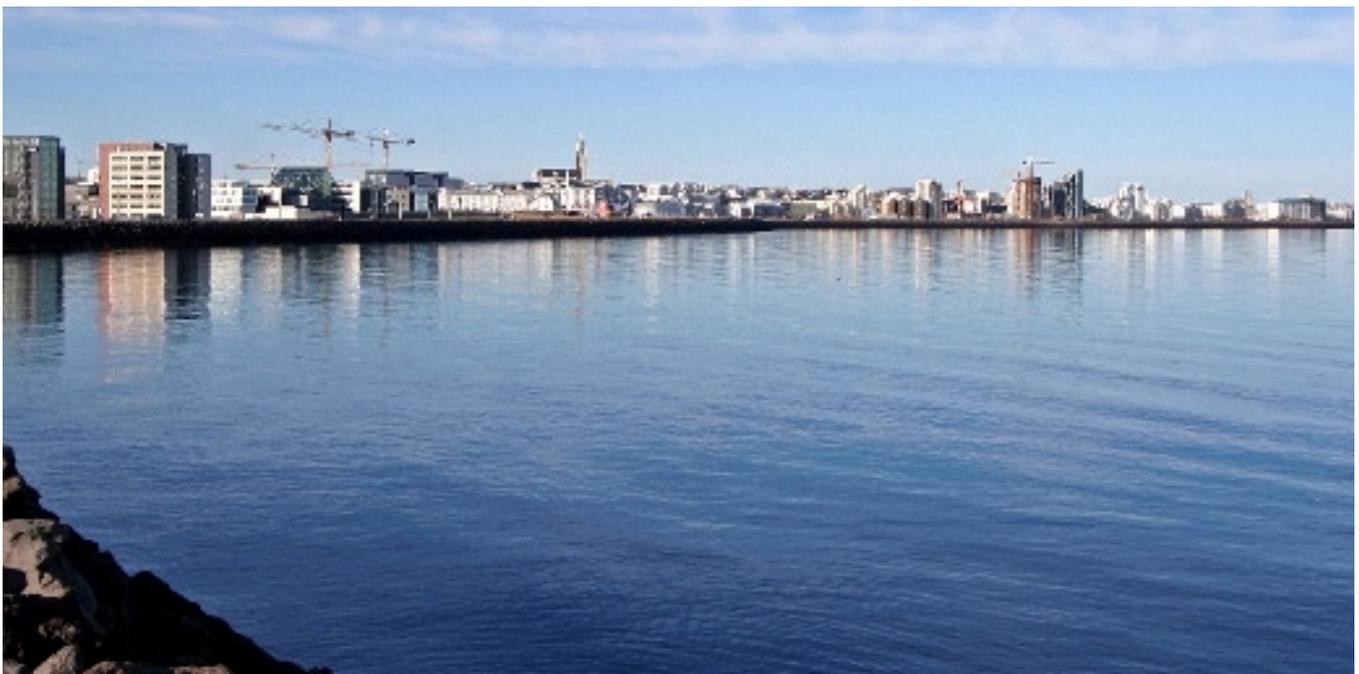
**13th Nordic Forum for BMT Nurses in Reykjavik
November 20-22 2008**

**Thorunn Saevarsdottir, Nanna Fridriksdottir,
Gudbjorg Gudmundsdottir and Sigrun Thorodds-
dottir.**

Since 1996 Scandinavian nurses working with blood and bone marrow transplantation have held a group meeting annually in the fall, alternating between the four Scandinavian countries, Denmark, Sweden, Norway and Finland. In 2004 Iceland became an active

member of the group and the first meeting held in Iceland was in November 2008. One aim of the group is to improve the cooperation between the transplant centers in Scandinavia, to study, develop and exchange knowledge, experience and ideas within Scandinavia.

The recent meeting held in November in Iceland was attended by 81 nurses from Denmark, Sweden, Norway and Finland and Iceland. The theme of the meeting was Patient and Family experience during BMT.



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EBMT NG National Groups Update (cont...)

The meeting started on Thursday afternoon with two sessions on complementary and alternative therapies for cancer patients and the participants being lead in relaxation and hypnosis, preparing them for the two-day meeting ahead. The Friday sessions focused on patient and family experience, starting with a presentation of the Calgary Family Assessment and Intervention model which is being integrated into nursing at Landspítali in Reykjavik. This was followed by three lectures, first on patients perception on symptom and symptom distress during and after stem cell transplantation in Sweden, second, on Icelandic patients experience of undergoing allogeneic BMT away from home, and third a Danish psychosocial intervention study for parents of children undergoing treatment with stem cell transplantation was presented. The final sessions were two stories, one shared by an Icelandic patient and another one shared by a mother of a young child who has undergone BMT. The Friday

meeting ended with a visit to the children's hospital and in the evening there was a welcome dinner downtown Reykjavik.

The meeting closed on Saturday at noon after national meetings, sessions on nutrition and neutropenic diet and discussion about the future of the Nordic Forum within the EBMT-NG, lead by Erik Aerts president of the EBMT-NG. It was decided to work on becoming a subgroup of the EBMT-NG and that the contact persons with EBMT would be the persons responsible for the last and the next Nordic Forum meetings, Thorunn Saevarsdottir from Iceland and Hanne Baekgaard Laursen from Denmark. They will work on the constitution and the strategy for the Nordic Forum group. Overall the meeting was rated successful by the participants who were also active in exploring the sights and shops of Iceland. Next year the Nordic meeting will be held in Copenhagen on November 26th - 28th.

Swiss National Group Update

Christel Pino Molina,

President, EBMT NG Swiss National Group

Last year's meeting took place in October in St. Gallen. The agenda comprised of elections, audits, education and new developments in autologous transplantation.

Elected as President was Christel Pino Molina, University Hospital of Basel, and, as Vice-President, Veronique Chapuis, University Hospital of Geneva. The next elections will be held in October 2010.

There will be a presentation about our experiences with the audits at the next EBMT congress in

Goteborg. Education will be a topic at the next Swiss National Group Nurses meeting in April 2009 in Aarau.

Dr. Urs Hess, Head of the Hematology Division, Cantonal Hospital of St. Gallen, gave a presentation describing new treatments for multiple myeloma. In future, numbers of autologous transplants are likely to be reduced.

This is all the news from the Swiss National Nurses Group,

Hope to see you all in Goteborg!

Austrian National Group Update

Birgit Keinrath

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Hello everyone!

I hope you all had a good time and that the start in the New Year is not too busy?

In the last update I recall telling you that some centres will move to a new place, so I asked them how the situation is at the moment.

Christoph from the Uniklinik Innsbruck kindly provided the below update;

The KMT-Center is at the new station since the 14 August 2008. We now have 12 normal beds and 8 for transplant. Before that we had 8 normal beds and 3 for transplant.

Since January 2009 we have been using laser therapy for transplant related mucositis and will test it for two months. I'm very inspired, but the physicians are still a bit sceptical.

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EBMT NG National Groups Update (cont...)

Laser therapy begins from the day of conditioning to the day +2 after TX, autologus as well as allos.

The tirolyan colleagues like the new patient rooms, they have a great overview of Innsbruck and the mountains and the rooms are very bounteous. But the rooms for the working staff are too small and the equipment bought is very cheep. They also saved on labour and so the work is very stressful at the moment.

Constantia from the AKH Vienna wrote:

We moved in August last year like the colleagues in Innsbruck but only had one week for the whole movement! Now there are 8 Intensive beds, 10 normal beds and 4 beds for the day hospital. However, we started with a huge problem: flooding in 2 of the patient rooms. Also the technical equipment didn't work as it should so there was a big issue with the air-conditioning, the laf-installation, the calling-system, the patient toilet system...I think everybody can imagine just how hard it was working in those conditions! I should also mention that not surprisingly it was mostly the nurses that had to deal with all of the problems; we didn't really get supported by the physicians...

Birgit from the St. Anna Kinderhospital wrote:

The completion of the research centre for children with cancer is finished along with the "prophylactical support in children with high risk during KMT" project which is now completed along with a further enhancement of the working-guide for quality management.

Like the colleagues in Innsbruck we have also started a trial period with the laser-therapy – if it helps against the mucositis as desired we are thinking of buying our own device.

That's it for now, greetings from Austria!



Uniklinik Innsbruck -KMT



AKH Vienna – KMT

Middle-European National Group Update

Eva Bystricka,

Charles University Hospital, Pilsen, Czech Republic
bystricka@fnplzen.cz

Cooperating centers: Croatia (Zagreb), Czech Rep. (Brno, Brno-pediatric, Hradec Kralove, Olomouc, Plzen, Prague-Motol pediatric, Prague-FNKV, Prague-UHKT, Prague-VFN), Estonia (Tartu), Poland (By

dgoszcs, Katowice, Lublin, Poznan), Romania (Bucharest), Russia (Petersburg), Slovakia (Banska Bystrica, Bratislava, Kosice, Martin), Slovenia (Ljubljana).

The Group is getting ready to meet in Göteborg at the EBMT 2009 congress, and to present its work and cooperation. Results of large international survey "Current protective isolation policy within East,

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EBMT NG National Groups Update (cont...)

Middle and West European transplant centres" were accepted for publication as an abstract and an oral presentation and will be presented during the Nurses Session 12: Multidisciplinary collaboration, on 01 April 2009 commencing at 10:20. In addition to this, results of "Nurse-staffing standards within East, Middle and West European transplant centres - a pilot survey" were accepted as a poster presentation.

During the EBMT 2009 congress, the group will meet on Monday 30, at 17:30 to discuss various SOPs that are displayed on the Group's web pages: www.ebmt.org/6NursesGroup/nurses17.htm, ongoing and planned research projects, questionnaires and any individual issues.

Several nursing SOPs are posted on the Group's web pages, to give an example of individual nursing pro-

cedures and to help facilitate JACIE accreditations in Eastern Europe. In 10/2008, the BMT centre in Pilsen (Plzen) was the first one within the Group to become JACIE accredited.

In September (26-28), 160 haematology and oncology nurses from the Czech and Slovak Republic met together during the annual educational meeting. Topics presented and discussed included multiple myeloma treatment and nursing, pain management, HLA typing and psychology issues, ongoing and past research projects and new prospectives. Unfortunately, due to language barriers and long distances it has not been possible to organize a similar meeting together with other foreign BMT centres.

EBMT (UK) NAP Group Update

Carol Charley, UK

charley@wymeswold1.freeserve.co.uk

The EBMT (UK) NAP continues to have good attendance. The group organised three study days in 2008. Our 35th meeting was in Liverpool, the European city of Culture, for 2008, in November. Topics included:

- Reduced intensity Allografts
- Supporting teenage and young adults
- Management of unrelated donors
Patient pathways
- Quality of life post transplant

Our links with the UK Quality Managers Forum meant that during 2008 we were able to hold joint JACIE sessions, at our meetings, and were able to support teams preparing for JACIE inspections.

Ongoing projects that the group is involved with are:

- The fungal assessment tool
- Sibling donor project
- The possibility of holding a patients forum at one of our meetings during 2009-02-05

In the financial climate our sponsorship for 2009 has been reduced, therefore we have only planned two meetings. On a positive note we have a new sponsor

ELF (Elimination of Leukaemia Fund) who are sponsoring a speaker at each meeting and also a travel grant for UK nurses and allied professions who would like to attend an educational meeting or visit another European BMT Unit. Those UK members who are interested should contact a committee member via the web site www.ebmt.co.uk

During 2009 we will be updating our database for UK BMT centres and there will be some changes to the committee. Already we have said goodbye to Helen Jessop, who has been on the committee since the beginning, nine years, and have welcomed Michelle Kenyon and John Murray

Our venues for meetings during 2009 are; 24th June - Reading Town Hall, Reading and 4th November - Derby Conference Centre, Derby.

Those of you that are attending EBMT 2009 should be very proud, as it is 25 years since the first meeting of BMT nurses in Europe. The EBMT (UK) NAP Group would like to acknowledge those nurses who had the foresight to organise that first meeting, because without them the EBMT Nurse Group would not be what it is today. A big thank you to Celeste Dye and Yvonne Hagen from the Netherlands, Jean Edwards and Linda Ward from the UK.

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EBMT NG National Groups Update (cont...)

Your committee members are:



Carole Charley – Chair



Louise Ritchie – Vice Chair



Joan Newman – Secretary



Michelle Kenyon – member



John Murray – member

One of the above members will take on the role of treasurer after our next committee meeting in February 2009.

Dutch National Group Update

Marjan Rademaker, Amsterdam
raatje2@hotmail.com

The Dutch National Transplantation Nurses Group was formed in 1985. We started with a group of nurses from 9 hospitals, mostly university centres, where autologous and allogeneic stem cell transplantations (SCT's) are performed in adults and/or children as well. Nowadays, we have a group of nurses from 16 hospitals; 4 hospitals perform SCT's both in children and adults.

The aim of our group is not only to get care for patients and donors more standardized but on a higher nursing level as well. The way we try to reach this goal is by taking part in development of nursing and multi-disciplinary guidelines. The last guideline we developed is advice for nursing care for patients with graft versus host disease. We've developed these guideline together with the HOVON (Dutch foundation hemato-oncology diseases in adults).

We meet 4 times a year on regular basis to exchange knowledge and experiences. Each year in May we have a meeting with a special theme. Last year we had a meeting with the Dutch stem cell patient association. Since then we realize our aims are partly the same and we cooperate to achieve success. The first thing we have developed together is a new version of a patient and donor information brochure.

Our national SCT group has variable sub-groups with their own attendance. At the moment these sub-groups are:

- Education and network / cooperation with patient association
- Late side effects
- Follow-up care

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EBMT NG National Groups Update (cont...)

Since 2000 we are a special interest group of the Dutch Association of Oncology Nurses. We take part in their yearly congress. This year we did a workshop session about the way to better inform patients and donors, late side effects of SCT and follow-up nursing care. The response of the audience was very positive.

We promote ourselves by giving lessons on haematology and oncology educations. Twice a year we used to

have our own newsletter but now we take part in the oncology nurse journal that appears 4 times a year and we have a webpage on their website.

Since 2006 most national nurses groups, including our association of oncology nurses, are united in V&VN (nurses and attendants of the Netherlands).

General Information

EBMT NG Board Contact Details

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General Information

Membership is open to nurses and health-care professionals who are actively working within the fields of blood and marrow transplantation or haematology, or who are committed to developing this sphere of nursing. Membership lasts from 1st January to 31st December every year, and must be renewed annually in November. If you wish to terminate your membership, you should inform the treasurer at least one month prior to the annual conference. Members will receive the following:

- Reduced registration fee for the next annual meeting of the EBMT-NG
- News bulletins and related BMT nursing news
- EBMT News, published three times a year

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General Information (cont...)

Membership fee

Form of payment:	Current members:	New member:
Bank transfer	40 Euros	40 Euros

EBMT NG Board Contact Details

Payment will only be accepted in Euros via bank transfer; no other currency or form of payment will be accepted. All current members will be reminded to renew their membership in November to ensure membership is valid when registering for the EBMT conference

For further information, please contact the Membership Administrator:

EBMT NURSES GROUP
Membership Administrator
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Phone: +34 93 453 8711
Fax: +34 93 451 9583
E-mail: nurses@ebmt.org

Further information about the Nurses Group is also available on the EBMT website at:
www.ebmt.org/6NursesGroup/nurses1.html

Next Issue – dates to remember!

The next issue of the NG Newsletter will be distributed in May/June 2009. Deadline for the submission of articles will be May 4th, 2009.

We will shortly make contact with you and we look forward to receiving your articles and updates.

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Sabine Degen
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Amelia Murst
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EBMT NG Communication & Networking Committee

Important Dates and Upcoming Meetings

Göteborg, Sweden
29th March - 1st April 2009



EBMT 2009
35th Annual Meeting of the European Group for Blood and Marrow Transplantation

25th Meeting of the EBMT Nurses Group

8th Meeting of the EBMT Data Management Group

Saturday, 28 March 2009
3rd EBMT Patient & Family Day

19 January - 12 June 2009

Zürich and St. Gallen, Switzerland
Haematology Course
hoefa1onkologie@kssg.ch



19 March 2009

UK Myeloma Forum Annual Scientific Day
London, UK
UKMF@hartleytaylor.co.uk



26 March 2009

London, UK
UK CLL Forum Annual Scientific Meeting
CLL@hartleytaylor.co.uk

March 29 - April 1, 2009

Gothenburg, Sweden

EBMT 2009
35th Annual Meeting of the European Group for Blood and Marrow Transplantation

25th Meeting of the EBMT Nurses Group

8th Meeting of the EBMT Data Management Group

Saturday, 28 March 2009
3rd EBMT Patient & Family Day
www.congrex.ch/ebmt2009/

17 April 2009

Salzburg, Austria
AHOP Frühjahrstagung
www.ahop.at/html/termin.htm#fortbildung

April 30 - May 3, 2009

San Antonio, Texas, USA
ONS Annual Congress
www.docguide.com/crc.nsf/congresses/2204331BD3F4BBE085257307005896C9

6 - 9 May 2009

Greece
10th International Symposium on MDS to be held in Patras,
<http://74.125.77.132/search?q=cache:ICeTOKvBAREJ:www.eae.gr/images/uploads/Preliminary%2520Programme%2520-%2520MDS.pdf+mds+symposium+2009+in+patras&hl=de&ct=clnk&cd=1&gl=ch>



12 May 2009

London, UK
British Society of Blood & Marrow Transplants (BSBMT) Annual Scientific Meeting
carla@hartleytaylor.co.uk
http://www.bsbmt.org/pages/1-BSBMT_Home_Page

21 - 25 June 2009

Vienna, Austria
11th World Congress of Psycho-Oncology
www.ipos-society.org/professionals/meetings-ed/congress.htm

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Important Dates and Upcoming Meetings (cont...)

3 - 6 June 2009

ESH EBMT Training Course
Genoa, Italy

The course will explore the major issues that have an impact on haemopoietic stem cell transplantation in children.

www.sispge.com/ped-bmt/

21 - 25 June 2009

Vienna, Austria

11th World Congress of Psycho-Oncology

www.ipos-society.org/professionals/meetings-ed/congress.htm

2 - 3 September 2009

St. Gallen, Switzerland

Internationales Seminar: Onkologische Pflege Fortgeschrittene Praxis

www.zetup.ch

September 20 - 24, 2009

Berlin, Germany

ECCO 15 and 34th ESMO

www.ecco-org.eu/%20Conferences-and-Events%20ECCO-15/page.aspx/216

2 - 6 October 2009

Gemeinsame Pflgeetagung von KOK, AHOP und der OPS im Rahmen der DÖSGHO 2009

<http://haematologie-onkologie-2009.quintx.info/>

15 April - 17 April 2010

The Hague (Den Haag, the Netherlands)

7th EONS Spring Convention

www.ecco-org.eu/

For details of related meetings, a regularly updated list of all meetings and conferences taking place, Click here

Details of various courses taking place in Switzerland can be found in the following website: Click here