



**Agenda for the EBMT Nurses' Group Board Meeting
Tuesday 28th April 2009
Amsterdam**

Present:

Erik Aerts (EA)	President
Arno Mank (AM)	President Elect
Michelle Davies (MD)	Secretary
Joachim Blankart (JB)	Treasury
Birgit Keinrath	Local Nurse Vienna
Sara Notley	EBMT Secretariat Support

Agenda item:	Discussion:
Previous Board Minutes, AGM minutes & Administrative items	<p>Minutes from the previous Board Meeting (12th December 2008) and the AGM in Gothenburg have both been signed off and put on the web.</p> <p>The need to continue providing a summary of the minutes was discussed. The Board decided that a summary would be provided for this meeting and a decision taken in September at the Board Meeting whether to continue after consulting the committee and National Group Chairs.</p>
Treasury Report	<p>JB gave an update on the NG accounts. Budgets for next year must be received by 1st September from all Chairs.</p>
Research Committee	<p>JB stated that the group have 2 projects underway:</p> <ul style="list-style-type: none"> • Current sexuality survey in cooperation with LEWP. • Looking at Patient Information Needs. • Possible further collaboration with LEWP <p>They plan to present their Action Plan at September Board Meeting.</p> <p>Donor Article The Donor Article has been satisfactorily peer reviewed and is due to be published soon in BMT.</p>
Communication & Networking Committee	<p>Newsletter MD gave the Board an update on CNC activities. The work-plan is going well and a number of articles have already been received. Hits to the newsletter (last edition) have increased.</p> <p>Guidelines for Contributors The document 'Guidelines for submission of articles' was approved by the Board. They suggested adding a point to inform and get approval from authors and okayed their use and addition to the web once revised.</p> <p>Website All info and links need to be checked before the launch of the new EBMT website (approx. Sep). EA will spend morning 22/05 with Secretariat making web changes prior to SC meeting.</p> <p>Applications Amelia stepped down after Gothenburg. No applications have been received yet</p>

	<p>–</p> <p>Sponsors EA expressed his interest in finding sponsors for the NG News. he will check with B Braun and PALL whether they are interested in continuing their sponsorship for the forthcoming year</p>
Exchange Visits / Travel scholarships / Conference Travel Grants	<p>Exchange Visits MD explained that an exchange visit was currently underway between Germany and Iceland. The return visit will probably be in September. an official application, CV and letter of motivation must be received, in addition to an abstract in Vienna.</p> <p>Scholarships MD confirmed that an official application had been received from Monica Kirsch and that she is keen to go somewhere that the RC is based or that specialises in Late Effects.. She will be expected to present an abstract in Vienna.</p>
Nuclear Accident Committee	AM summarised an email from M.Fliedner reporting a fruitful meeting had taken place in Gothenburg. She is still trying to include nursing aspects into the NAC and is keen to set up a session at EBMT 2010.
Outreach Committee	AM told the Board that the Outreach Committee were eager to collaborate more with EBMT activities. AM encouraged them to take advantage of the exchange visits and scholarships at their meeting in Gothenburg. He has been invited to Pilsen to speak in October.
Collaboration with the EBMT Working Parties	<p>Late Effects MD provided an overview of her attendance at the LEWP Meeting in Gothenburg. The group is very eager to continue working with NG and asked MD to list possible future joint projects. on: I) 'the role of nurses in Late Effects' and II) 'Education for paediatric post transplant'. JB will ask the RC if they would be able to take these projects on.</p> <p>A decision was taken in Gothenburg to develop the sexuality survey as a separate project. Corien will lead the project and use her own study data as a baseline for the new protocol. This would be a joint RC and LEWP project tbc at next LEWP meeting in sep/oct. Corien and MD will both attend this meeting.</p>
Paediatric Nurses Group Committee	EA gave a report on the development of the PNG. They have written an article to introduce themselves in the next NG Newsletter and aim to launch a survey on educational needs and the role of paediatric nurses in time for the Haematology Course in Genoa with the PDWP. Applications The 3 applications were discussed all Board members felt that Merja (Helsinki) was the strongest candidate, offering a solid scientific background.
JACIE	EA stated that he had not received an update from Mairead. It remains unclear whether nurses are able to be inspectors and what the nurses role is within JACIE. The next JACIE Board Meeting is in October. JB suggested working on a hand-out to accompany the NG presentation at JACIE Training Courses.
National Groups / Forums	AM gave an update on all NGs: NL – Very active at the moment, getting more involved with haematology issues to get a broader perspective. EA stated that the EBMT logo should appear on their statute if they are an EBMT Group. DE – No new info since Gothenburg. ESP – Busy organising Study Day in May.

	<p>IT - No new info since Gothenburg. AUS – Have provided AM with statutes. CH - No new info since Gothenburg. UK – New president tbc. Carole will email post elections. FR – Still trying to set up a group. TR – AM has had email contact with 2 nurses from Turkey but was unable to meet them at Gothenburg. Mutlu Arat is also keen for his nurses to form a group NF – An official decision was taken to become the Nordic Forum. Current chair is Denmark and this will change every year. ME – Middle Eastern Group (no news)</p> <p>EA requested a number of NGs replace the EBMT logo in their statute with the new one.</p>
<p>Organisation</p>	<p>EA requested all NGs and Chairs be sent templates for NG stationary, slides and documents etc.</p> <p>EBMT Board EA gave a brief summary of the EBMT Board Meeting; Kim Champion was now contact person for the PCTC, 2013 EBMT venue to tbc in the June Meeting when the EBMT Exec. Dir. will also be discussed. A. Madrigal has joined the Board as Pres.Elect.</p> <p>Structural Overview The Board discussed the revised organigramme and agreed to use the main Board template but to add - a Committees box - collaboration with WPs - change Middle to Eastern European then to add to website.</p> <p>Election Process The Board agreed that the on-line voting system suggested by Lissa was very good, though a little expensive. They decided to look at more free on-line options.</p> <p>Announce elections = Email in Sep and Newsletter Call for nominations = 27th Sep (email) Closing date for nominations = 26th Oct Voting Forms out = 9th Nov 12am Closing Date for votes = 30th Nov 12am</p>
<p>Education Initiatives</p>	<p>AM gave an update on activities with:</p> <ul style="list-style-type: none"> • Genzyme . G.EU and G.USA have given go ahead to develop an ed. tool for nurses and HCPs. EA will meet with them in San Antonio to establish clear aims, time-line, etc. The Board discussed Aleksandra Babic's email and decided to suggest she is involved with the EBMT/Genzyme project rather than supporting her in a separate project. • Pierre Fabre Medicament Want to involve nurses in possible projects but is unclear at the moment what this would involve, EA will provide further update as appropriate. <p>ESH Handbook T.Massi is enthusiastic about nurse involvement and has suggested adding a nurse's chapter or creating a separate handbook for nurses.</p> <ul style="list-style-type: none"> • Project Turkey Want to involve EBMT-NG in on-line educational project for paediatric

	<p>nurses Novartis EA sent 2nd draft of Ed. Initiatives project re CML and CLL. Re article Educational Needs for Nurses in EU Novartis are working on changes and will resend to EJONS in a couple of weeks.</p> <ul style="list-style-type: none"> • Haematology Course 2010 in Turkey This course is held 2 yearly and a request for input on lectures from EBMT-NG has been made. Waiting to hear more info on dates for the course an expectations of input from the NG before a decision is made. • Autoimmune Diseases WP EA reported that the AIWP President, has approached him to request NG participation in a study day, as part of the HSCT for Sever AIDs International Congress in November in Florence. EA will ask for a more active proposal, explaining what he would like the NG to do. NHL (Roche) Roche is reviewing their budget. This year they promise to be supportive of EBMT projects. • Celgene AE reported lots of activity between Celgene and EBMT-NG. An application to review the video has been received. It will be in several languages with the EBMT logo on it. AE a meeting will take place in July in Brussels between Celgene, patient advocates and MDS patient group. • MDS Foundation (USA) Have already expressed an interest in having a 2h symposium at Vienna (poss with Celgene and Novartis) and are keen to discuss further collaborative projects. Abstract 'MDS –nursing Care and Education Needs' sent to ASH in collaboration with Celgene and MDS (USA). • GVHD DVD online Reports that some colleagues have not been able to access the DVD were received during the Congress • Others AM suggested that an Educational Committee be established, since the amount of projects keeps growing. The Board decided to discuss this in September.
Scientific Committee	<p>AM and EA reported on the SC. AKM/Congrex told them costs need to be dramatically reduced; less invited speakers, chairs, rooms, etc. The Board agreed that they should all chair more sessions next year The SC received a lot of evaluation forms – feedback was generally satisfied. Some speakers felt that aims and objectives for sessions needed to be clearer. Isilda will be standing down after Vienna.</p>
EBMT 2009	<p>Review:</p> <ul style="list-style-type: none"> • Pre meeting study day It was felt that the 2 programmes had worked well but many people had attended the basic one due to language difficulties. It was also decided that someone should officially open and close the day. • National Group Meetings All felt the format used this year for meetings and presentations had worked well and should be used again next year. The Board decided that any proposal and/or guidelines developed should be translated and shared on the web. • Closing & Prizes The Board noted good attendance at the ceremonies. The same prizes should be sought at the sponsorship meeting for next year. JB suggested the prizes be promoted better and announced on web like physicians. • Distinguished Merit Award The Board discusses 3 candidates suggested by EA.
EBMT 2010	<ul style="list-style-type: none"> • 4th Patient & Family Day

	<p>BK stated that 6 workshops were to be organised; 1 paediatric and 3 together, using a mix of nurses and physicians. It will not be held in the Congress Centre. TC due to be held in June.</p> <ul style="list-style-type: none"> • Sponsorship Meeting Scheduled for 22/06/09. EA, MNiC and BK to attend. EA to mention symposia. • Press Releases EA needs results of best abstracts for press; 6 physicians, 2 nurses. He urged the Board to be proactive and contact all their press contacts. • Organisation Membership-There has been a shift from individual memberships to more centre memberships. As of March 09: 591 members, 33 of these are individual members. It was agreed the process developed with the secretariat works well,
PR / Strategic Plan	<p>Amgen meeting in Vienna May 15/16th re skeletal care, possibly joint project with EONS. Wait for more info EA presenting at ONS congress on MDS on behalf of EBMT NG MDS meeting in London organized by Celgene for patients/advocates in July-2nd: EA will represent the EBMT NG. EA represent the EBMT-NG in Freiburg (DE) Patient advocate for CML meeting in Lisbon 26-28th June: Decision: The Board won't join this meeting. FEPI- Simona Calza contacted EA re collaboration. EA fed back to Simona that FEPI should approach EBMT-NG with a formal proposal. ECCO- There are two free registrations to attend the conference in Berlin in September. If the Board will attend this meeting: tbc ONS- meeting organised next week with EA, AM, MD and reps from ONS board and BMT SIG group. Feed back post meeting.</p>
Goals EBMT NG 2009	<p>EA provided a pp slide with the goals for the NG for 2009. The Board has approved the goals in March 2009.</p>
Next Meetings	<p>A decision was made to have a 2 day SC meeting in December but to postpone the usual Dec Board meeting until January. A 2 day board meeting in Hamburg on 9-10th of Jan 2010 was agreed.</p>