



**EBMT Nurses Group Board Meeting  
Sunday 16<sup>th</sup> December 2007  
Florence**

Present:

Monica Fliedner	President
Erik Aerts	President Elect
Mairead Ni Chonghaile	Secretary
Joachim Blankart	Treasurer
Letizia Galgano	Local Nurse Florence
Simona Calza	Local Nurse Florence
Lissa Perteghella	Administrative Support
Eoin James Mac Hale	EBMT Office

**Introduction**

Monica commenced the meeting by welcoming everyone and thanking them for attending.

*Action points in italics*

**1. Minutes of Previous Meeting**

No changes required to be added to the last meeting's minutes.

*LP to add the Summary of the minutes for the September 2007 meeting to website.*

**2. Matters Arising from Minutes**

It was agreed that most matters would be addressed in today's meeting agenda. JB raised the issue that was brought up at the last meeting when discussing a possible meeting between Prof Francesca Albarani, President of GITMO and the NG Board. Letizia asked if it would be possible for both parties to meet on the Monday at EBMT 2008. National Group meetings were still to be confirmed and arranged and it was decided that a day and time could be worked on. It was clarified that it would probably just be EA and MF who would meet with Francesca on the Monday afternoon.

*Simona will send minutes of meeting to NG Board in January.*

*Guest pass will need to be requested for Francesca.*

**3. Editorial Sub Committee (ESC) now known as the Communication & Networking Committee (CNC)**

LP provided a brief update on the current work plan for issue number 3 of the NG Newsletter and included data regarding the number of visits to the last NG Newsletter which had been a total of 59 visits, this could include multiple visits by the same visitor along with EBMT office visits.

*MF would provide a Dear Members letter along with News from the Board and would highlight events to look out for at the conference hopefully before Christmas in time for Issue N°3 distribution.*

*EA will send an article about Travel Scholarships for Issue N°3.*

*MNiC suggested a conference overview section could be added to Issue N°3 and confirmed that she would provide something before Christmas.*

*Vivianne & Simona to provide article on Paediatric Working Party Meeting in Poznan in June 2008.*

*MF will remind Novartis about the symposium advert article.*

*EA to contact Amelia Muerst and see if she would be interested in joining the committee and MF to contact Sabine Degen and formalise her joining the committee.*

As in previous years a joint meeting with the board and the CNC will be held at EBMT 2008, Tuesday at 8am has been arranged.

MNiC reminded everybody that after EBMT 2008 the Board should request a list of all the nurses that attend so that they can be added to the mailing list for Issue N°4 of the NG Newsletter.

#### **Research Subcommittee (RSC) now termed as Research Committee (RC).**

The GvHD CD was discussed at length and the following is the agreed distribution list and set of remaining action points:

<b>Distribution List Details</b>	<b>Letter accompanying DVD</b>	<b>Mailing details</b>
*All current individual nurse members along with CIC nurse members. If there is no nurse listed at the CIC then a copy should be sent to the PI of the centre. (1 copy to each)	Monica to draft letter to accompany DVD	<i>LP to send mailing list to production company who will distribute and send from UK.</i>
80 copies reserved for the EBMT Board, Major Sponsors and Contributors	Monica to confirm distribution list and draft accompanying letter	<i>LP to await draft letter and send to mailing list that Monica will confirm</i>
**250 Copies to Florence for distribution at EBMT 2008	No letter required	<i>JB to send address in Florence to production company in UK for them to send.</i>
Extra Copies	TBC	TBC

\*individual members that have paid 2008 fees

\*\* It was decided that the 250 copies at Florence would be distributed in the following way. An announcement would be made at the opening session that attendees interested in obtaining a copy can collect the DVD at the EBMT stand. A check list should be prepared to ensure that people collecting the DVD are EBMT NG members and principally nurses.

*JB will contact Production Company to request a copy of jacket cover for review before DVD is sent out.*

JB reported that the RC had held a TC meeting in November - no minutes of this meeting had been received to date. It was also confirmed that no minutes had been received from the September meeting in Amsterdam.

Because of the recent election 2007 results, Arno Mank and Michelle Davies had communicated to the RC that they would be stepping down from the RC to take up their positions as president elect and secretary respectively.

Arno had communicated to JB that Simon Clare, Carin Potting and Becky Stone would remain in the RC with Carin Potting the choice as chair, and that they were hoping to send CVs of people that had indicated an interest to join the RC before the Abstract Selection & NG Board meeting in December. These CVs had not arrived and therefore could not be taken into consideration. JB to ask the RC to ensure CVs arrived with the NG Board before 15<sup>th</sup> January. However the board stated that the recent election results did not alter the agreement made at the joint meeting in September where Simon Clare & Carin Potting had stated that they would be the 2 members up for re-nomination this year and Joachim will contact them to inform them of that and ask for brief CV's to be sent to the board for consideration.

Once all CVs have been received JB will contact Arno to explain that the Board will make a decision about who will sit on the RC post EBMT 2008.

### **NG Board Elections 2007**

LP confirmed the number of votes received within the Friday 9<sup>th</sup> November deadline.

Arno Mank – President Elect (yes = 28, No = 1)  
Michelle Davies – President Elect (yes = 16)  
MNiC – (yes = 13)

MF confirmed that Arno Mank and Michelle Davies would be joining the NG Board at the end of EBMT 2008, Mairead would step down and join the Scientific Committee.

### **EBMT 2008**

*MNiC will write to the NG Board with some definition of the roles and responsibilities of the Scientific Committee (SC) leading up to EBMT 2009 for comment. Once agreed AKM will also be informed.*

MNiC enquired if the SC would have access to the existing administrative support from the EBMT. The Board agreed that this support would continue but that the support would be more clearly defined at a later date. It was likely though that this support would continue in the sense that support would be provided at abstract selection meetings and at the conference.

*MNiC to contact all abstract reviewers to say thank you and request AKM list them as members so that they are eligible for free registration at the early bird fee.*

*MNiC will attend the NG Board meeting at EBMT 2008 as secretary along with providing minutes as Michelle Davies will be unable to attend the meeting in Florence.*

*It was highlighted that all NG Board and approved committee changes should be updated on the EBMT NG website asap after EBMT 2008. LP to action.*

### **National Groups Update**

#### **Switzerland**

National JACIE day had taken place in Switzerland in November. EA had received an update but had had to re write it for NG Newsletter purposes.

#### **Germany**

The Group's 10<sup>th</sup> Anniversary had been celebrated in Kiel last November, they have a new chair (Ralf Schmacker). Sara Zulu had received an update and would edit it before submitting it.

### **Spain**

Cristina Gallego will not be attending EBMT 2008 in Florence as she is pregnant – she hopes to provide EA with the name of an alternative person who will take her place

### **Dutch Group**

No news or update received.

### **UK**

A few changes to the group had been reported and these changes had already been reflected in the NG website.

### **Austria**

The statutes were reviewed and it was agreed that the translation into English lead to various misunderstandings. It was agreed that EA would ask the group to provide the original german version to clarify the words lost in translation.

### **Middle Europe**

Website changes that the group had requested had been carried out. The Board discussed the groups list of standards/recommendations, which everyone agreed was a positive step. However, it would not be possible to officially approve the standards unless more detail behind the content was available. It was also still unclear what the group was requesting.

It was agreed that the list is fine for their own internal use but should not at this stage be associated with the EBMT NG. *It was agreed that in the meantime the list should be removed from the website (LP) as there is no facility for restricted/member only access.*

*EA to suggest they re write the section that refers to JACIE standards by removing the use of the word must adhere to....rather than more suggestive vocabulary as the list is a set of recommendations and not standards or requirements. EA will also request that they remove his name from a recent reference to him with regard to a grant received by the Swiss Haematology Group.*

### **France**

EA in contact with Sylvie but she has had little time to provide an update of further developments.

*EA to contact AFITCH president.*

### **Nordic**

The Nordic NG held a meeting in Finland 25<sup>th</sup> & 26<sup>th</sup> November. EA will email the board their latest news. In short however, they don't see any benefits of forming a national group, too many colleagues from different countries being the main source of concern. The question of whether or not to provide them with a room at EBMT 2008 was raised if they fail to see the need to or have no intention to form a group.

### **Greece**

Following a JACIE course in Athens a group are considering forming an NG for Greece. The NG board offer any support or assistance they can in helping the group form.

## Turkey

Sultan Kav (President Elect EONS) discussed at a recent EONS meeting in Brussels the prospect of Turkey forming its own NG group. *EA to report back to board.*

During this discussion MF took the opportunity to bring the letter she had received from the 5<sup>th</sup> **National Bone Marrow Transplantation and Stem Cell Therapies Congress** to the attention of the board.

After some discussion it was agreed that MF would attend the congress and provide a presentation/lecture on Mucositis, Tom van Boxtel on Venous Access Devices and MNiC on GvHD. The Congress would take place in Antalya in March 2008 (before EBMT 2008). Questions for an exam will need to be prepared for certification purposes. All expenses would be covered by the conference organisers.

*MF to clarify if the above lecturers will be providing their services on behalf of EBMT or individually and report back to the board.*

## Sexuality Brochure

LP had provided quotes from 5 different companies based in Barcelona to translate, produce and distribute the German Sexuality brochure into 5 different languages. After careful consideration and contemplating the feedback from the 4 NGs (below) that had responded to requests asking if it was necessary. The board agreed that it would prioritise distributing the GvHD DVD and then re evaluate the financial situation. It was agreed to postpone decision regarding the sexuality brochure until the DVD was distributed successfully and perhaps leave this as a decision the newly formed 2008 board would make.

Response from NGs following request to find out if they would welcome the brochure in their language, only 4 National Groups responded:

UK – No  
Middle EU – Yes (Czech)  
Swiss – Yes (Italian & French)  
Austria – (Polish)

## EMRO (Eastern Mediterranean Regional Organisation for BMT) (Egypt, Jordan, Lebanon, Oman, Saudi Arabia and Bahrain)

Currently working on a set of statutes as they are keen to be affiliated with the EBMT, they will have another meeting in January. MF noted that Saudi Arabia was very keen to help support Egypt financially. MF will update board as and when new information is received.

## Education Initiatives

### Myeloma:

MNiC thanked everybody for their collaboration and comments. MF suggested that something about this could be mentioned in the NG Newsletter. *MNiC to work on something and send to CNC.*

### Education Subcommittee:

MF reported that she hadn't really had time to dedicate much to the book. It materialised that WPs had not been asked for comment and requests sent out at short notice. *MF to try and ensure that next time the NG is asked for comment first time around.*

### Novartis:

A total of 271 responses from 25 countries were generated by the questionnaire, EA has been in touch with Novartis re how to proceed. Novartis Europe has replied that they are still working on it.

*EA to send slides of Novartis questionnaire to the board.*

### Alexion:

MNiC raised the issue of when the proposed Advisory Board should meet. Tuesday 4-6pm has been suggested as the best time. The difficulty of finding nurses with an interest in PNH for the advisory board was discussed.

### **Nuclear Accident Sub Committee**

MF reported that 25 doctors had attended the recent educational course that had taken place. It had provoked controversial discussions and created good participation. MF confirmed that lecture had been well received. Panel discussions had also highlighted the many issues still to be fully explored and raised the objective to get teaching modules together.

MF confirmed that once she steps down from her presidential duties of the EBMT NG Board she would very much like to continue as a member of the **Nuclear Accident Sub Committee**.

### **EONS - overview of the Advisory Board & AGM**

MF attended the EONS AGM in Barcelona and EA attended the recent advisory board meeting in Brussels.

EONS will no longer liaise with FECS but directly with ECCO. Erik had been instructed to deal directly with Sarah Faithfull and not Jan Faubert. EA also confirmed that they had said they are not currently working on any Haematology Projects, but that they will however develop TITAN..

After discussion the board decided definitively that they would no longer continue as members of EONS or apply for accreditation with EONS.

*JB to cancel membership with EONS*

### **Collaboration with WPs**

MNiC confirmed that the Late Effects WP had cancelled its meeting in Rome and was therefore unable to provide any feedback. There are 4 projects that are appropriate for NG involvement

- The role of the family member
- Sexuality
- Fatigue in children undergoing RIC
- Myfortic GVHD study (*MF to contact Gerard Socie*)

*MNiC to follow up on these opportunities.*

It was agreed that the LEWP was keen to include nurses within the WP.

MNiC raised the question of sending Viviane & Simona to the Paediatrics WP was a coincidence or if a specific representative role should be created and budgeted for? MF suggested that it would be wise to see how the relationships between nurses and WPs develop and then make a decision. It was agreed however that nurses from NG committees attending WPs courses should report back to the NG Board and not the Scientific Committee in the first instance.

### **Honorary Membership Requirements**

LP commented that Fiona had not been able to provide any written evidence of requirements used for selecting EBMT Hon. Members. She had indicated though that experience of founding members was highly relevant. However, the board agreed that the latest EBMT Hon members didn't appear to meet these min requirements.

The board agreed to rename Honorary Membership as Distinguished Merit Award.

*MNiC to edit the list of requirements document and send to board for final comment.*

### **JACIE**

MNiC thanked the board for their feedback on the JACIE handbook comments and commented that she had received responses from all but one of the nurses that had attended the inspector's course. *MNiC to follow up and report back.*

A lengthy discussion about the JACIE requirements for nurse inspectors followed led by Eoin. The JACIE board is keen to investigate the possibility of nurse inspectors. The board expressed concern that the current requirements for a nurse inspector (the 5 years apheresis experience) is not adequate and excludes a number of people who would be well qualified to be inspectors. Also the Board feels that apheresis experience alone is not adequate and needs to be thought about along with a proposal formally drawn up and discussed.

*Eoin will take back NG board suggestions to JACIE, meanwhile the NG board will look into possibly 1 or 2 nurses suitable to attend the next Inspectors course as trainers/inspectors.*

Eoin was keen to clarify who from the Board, would continue as the nurse contact for JACIE? The Board confirmed that although MNiC would be stepping down after EBMT 2008, it was wise to ensure continuity and suggested that MNiC could remain as JACIE's EBMT nurse contact. This was agreed.

*MNiC confirmed that she was still working on the questionnaire and would send it to the board in the new year for comment.*

### **Constitution/Strategic Plan.**

*MNiC will update constitution document with date that doc was revised and agreed. This would be forward to LP to add to website.*

### **Treasurers Report**

JB provided the board with the latest update on its cost cutting savings, after relooking at where and how money was being spent a total of €7000 had been saved. Second half of year would be funded by the AMGEN money.

*JB to send MF updated budget to indicate savings that MF would highlight at the next EBMT Board meeting in January 2008.*

## **AOB**

Everybody agreed that the AGM format was OK – *MNiC to email AKM re AGM (slides etc)*.

LP raised the issue of the user analysis questionnaire that had recently been sent by Stephen Jones at the EBMT office in Barcelona, in case anyone needed any further information she was happy to discuss. Everybody agreed that they had not had time due to the busy period but would ensure it was sent to Stephen before the 21<sup>st</sup> December.

On behalf of the NG Board MF formally thanked Eoin for all his help and support over the last year or so and invited him to attend the AGM at EBMT 2008.

## **Next Meeting**

AGM at EBMT 2008 in Florence (Thursday 3<sup>rd</sup> April 2008, 08.00 -13.00hrs)