

**EBMT Nurses Group Board Meeting Minutes**  
**Saturday 6<sup>th</sup> and Sunday 7<sup>th</sup> September 2008, Milan**



**Present:**

Erik Aerts (EA)	President
Arno Mank (AM)	President Elect
Michelle Davies (MD)	Secretary
Joachim Blankart (JB)	Treasurer
Elizabeth Wallhult (EW)	Local Nurse Gothenburg
Inger Andersson (IA)	Local Nurse Gothenburg
Lissa Perteghella (LP)	EBMT Secretariat Support

**Present Saturday 6<sup>th</sup> September only:**

Sarah Liptrott (SL)	Research Committee
Eva Johansson (EJ)	Research Committee
Corien Eeltink (CE)	Research Committee

**Introduction:**

EA commenced the meeting by welcoming everyone and thanking them for attending, he also invited everybody to introduce themselves individually.

Agenda Item	Discussion
<p><b>Research Committee</b></p>	<p><b>Update/Report from JB</b>                      JB took this opportunity to provide some background information for the new RC members in attendance. Becky Stone had recently stepped down as chair therefore it was suggested that <b>as a priority a new chair should be discussed</b>. In addition JB and the board suggested the following things that the RC should consider:</p> <ul style="list-style-type: none"> <li>• Suitable topics for future projects in line with research priority survey results.</li> <li>• Links with National Groups</li> <li>• No of conference calls and face to face meetings required.</li> <li>• A short introduction for the next issue 5 of the NG newsletter.</li> <li>• Review NG website and amend as necessary.</li> <li>• Review the current terms of reference</li> </ul> <p><b>Review PCTC process and collaboration (Prospective Clinical Trials Committee)</b>                      Zoe Doran (ZD) has approached the NG for 5 volunteer reviewers as she's keen for nurses to be more involved. SL and CE have both volunteered and it was agreed that it would be interesting to evaluate the process post review.</p>
<p><b>Previous Board Minutes &amp; Administrative Items</b></p>	<p><b>Matters Arising from Previous Minutes</b>                      LP provided brief overview of costs and process involved in making the GvHD DVD available online. It was agreed that only the final footage used in the DVD would be required in AVUI file format. EA commented that it might be something that the main EBMT board could be interested in funding. Updating the DVD may also be a consideration before making it available online.                      It was agreed to get a further quote in addition to LP working with Stephen Jones at the Secretariat to investigate the possibility of uploading the DVD online without Interel's service.</p>

<b>Treasury</b>	<b>Budget Update/Report</b> JB provided brief overview explaining that there were still some funds left in the budget for the remainder of 2008. This included what was left of the AMGEN and O'Donnell fund. JB confirmed that there was sufficient funding to cover the GvHD DVD online costs if necessary.
<b>Scientific Committee (SC) Update</b>	<b>EBMT 2009 Preparations Overview:</b> <b>Pre Meeting Study Day</b> IA confirmed that only 1 further speaker is required and is well sponsored by several companies.  <b>Other Business</b> The election and voting process will be decided at the next meeting in December. This discussion lead to the Board making a decision that a Standards of Practice (SOP) regarding all election and voting procedures should be introduced into the NG constitution and adhered to by all committees in their terms of reference. In the meantime an announcement text should be drafted to invite members to join the Scientific Committee (2 members will be leaving after EBMT 2009) so that new members can be selected well before EBMT 2009. Advert should go out in October and 4 weeks should be provided for candidates to respond.
<b>Exchange Visits/Travel Scholarships</b>	<b>Update/Report from MD</b> Yet again, no applications had been received, which raised the question of what could be done to improve this situation. It was agreed that funding for Exchange Visits will go up from €450.00 to €750.00 – in addition free registration at the conference was considered along with extending the deadline.  It was agreed to extend the deadline for Exchange Visits and Travel Grants to 30 <sup>th</sup> May. The Educational Scholarship deadline would remain as 1 <sup>st</sup> January. An email announcement will be sent in November to remind members.
<b>EBMT 2009 Update</b>	<b>Data Management</b> JB provided overview re his presentation last year; he has been invited again and has accepted.  <b>Fee Structure</b> Nurse registration fee increased by € 10.00. The last time the fee increased was in 2000.  <b>National Group Meetings</b> It was agreed that already established NGs would meet individually with the Board. For members that may be interested in forming an NG or want to know more about NGs, a meeting will be implemented where the Board will provide a brief presentation and then invite members from different countries to join up and get to know each other. MD has offered to present at this meeting.  <b>Best Abstract</b> Funding for Best Abstract will consist of 3 prizes and will be provided by Fresenius Biotech.  <b>Best Poster</b> Will be funded by Novartis Oncology.

<b>Research Committee Meeting Update</b>	<p><b>Report</b></p> <p>After their meeting in the morning the RC joined the Board to provide an update. JB confirmed with the RC that their travel/accommodation etc would be paid for to attend EBMT 2009.</p> <p>AM informed the RC of their previous idea to present Research Committee history and provide an overview of the previous years of EBMT nursing research, it was agreed this would be a good idea but quite a big task. It was agreed that CE and AM will look into it and if possible work on it together.</p> <p>The RC had a few queries with the terms of reference and these were clarified during the Board meeting and will be amended by MD along with the T&amp;R for the other sub committees.</p> <p>After agreement and encouragement from SL and CE, EJ has offered to chair the group as long as other members have no objection. JB will communicate this to the rest of the RC.</p> <p>With regard to the GvHD DVD the group is keen to execute a survey to evaluate it. – Whoever the DVD is for will dictate who the survey is directed at. Several further discussions were raised about the DVD including a possible workshop at EBMT 2009 to evaluate the DVD with a view to providing an abstract.</p> <p>Areas the RC will focus on are:</p> <ul style="list-style-type: none"> <li>• Effectiveness of patient Information including literature review</li> <li>• GvHD DVD Survey &amp; Evaluation</li> <li>• Survey about written information for patients</li> <li>• Research Agenda</li> </ul> <p>An agreement re the chair of the RC should be made before communicating decisions made by the group to the Board. This included decisions about rooms required at the conference.</p>
<b>Communication &amp; Networking Committee Update</b>	<p><b>Report</b></p> <p>MD provided an update from CNC and referred to minutes from their last TC. It was agreed and accepted that 3 newsletters would be published each year and continue to bear in mind that if it was difficult to produce 3 the possibility of just 2 editions could be considered.</p> <p>It was agreed to add the deadline dates for the next 3 issues in issue 5 of the newsletter</p> <p><b>Timeline</b></p> <p>It was agreed that June would be a better month to distribute Issue n<sup>o</sup> 7 of the newsletter.</p> <p><b>Terms of Reference</b></p> <p>Terms of reference were agreed and MD will amend and distribute to the Board.</p> <p>LP reported that number of visits to issue 4 of the newsletter had risen from 96 to 146.</p>
<b>JACIE Update</b>	<p><b>Report</b></p> <p>EA had received a report from Mairead NiConghaile – it was agreed to discuss again at the next meeting in Gothenburg re how to move things forward.</p>
<b>Nuclear Accident Committee</b>	<p><b>Report</b></p> <p>AM reported that there were no significant changes since the last meeting. Monica Flidner had attended the meeting.</p>
<b>Collaboration with the EBMT Working Parties</b>	<p><b>Late Effects WP</b></p> <p>Their next meeting is due to take place on the 11th November in Paris. After some discussion the Board agreed that it was a good idea to have some NG presence within the WP. The Board agreed that MD would attend the meeting.</p>

	<p><b>Outreach</b> EA and Vladimir Koza (VK) are in contact. It was noted that the outreach bulletin does not include any nurse input although VK is keen to encourage input from the NG. No real task for the NG at this stage but it was considered important to keep the item in the agenda and continue to discuss.</p>	
<p><b>Collaboration with the Paediatric Diseases Working Party (PDWP)</b></p>	<p><b>Report</b> EA provided a report/overview of the Poznan meeting along with his meeting with Christine Peters (new Chair of the PDWP). She is keen to introduce a Nurses Advisory Board within the WP. A training course will be taking place in Genoa and will include nurses.</p>	
<p><b>National Groups</b></p>	<p><b>Reports</b> AM confirmed that there was very little to report as most National Groups had not provided an update.</p> <p><b>New Groups</b> AM provided brief overview regarding the countries that were considering forming an NG:</p> <p><b>Nordic Group</b> – AM &amp; EA to attend meeting in November to move the NG forward. <b>France</b> – EA still in contact with Olga S. (Nurse from Lyon) and Mrs. Hoarau (AFTICH)</p> <p><b>Terms of Reference (TR)</b> The TR were reviewed and amended by the board focusing mostly on the group’s communication responsibilities and ensuring the TR didn’t conflict with the constitution.</p>	
<p><b>Education Initiatives</b></p>	<p><b>Report on Activities:</b></p> <p><b>Novartis</b> Advisory Board meeting will take place 4th October in Frankfurt. EA and AM will participate. Possibility of collaboration with MDS Foundation. (Meeting will take place with representatives from the MDS Foundation). EA has been in contact with MDS via TC – they are keen to optimise educational needs for nurses including Patient Information Material.</p> <p>AM will join the MDS Patient Seminar on October 2nd and 3rd in Frankfurt. After the October meeting in Frankfurt a meeting with Novartis is planned in order to discuss future educational programmes. CML project looks likely along with MDS collaboration EA will inform the Board as soon as the article with the title “Defining the scope of haematology nursing practice in Europe” is accepted by EJON.</p> <p><b>2nd ESH-EBMT Training Course for Paediatricians and Paediatric Nurses on HSCT in Children &amp; Adolescents</b> EA reported that Simona Calza will shortly be sending G. Dini the final programme for the Genoa based course – <b>EA will report back when he has more news.</b></p> <p><b>NHL (Roche) Binder Project</b> EA provided a brief overview of his recent communication with the Swiss Oncology group and EONS – <b>EA will report back to the board when he has further details.</b></p> <p><b>Alexion</b> AM provided overview of meeting in Florence regarding their new drug being introduced into the market. No further actions on the NG Board’s part as it was agreed to wait for Alexion to approach the NG should they be interested in their involvement.</p>	

	<p><b>Celgene</b> EA reported he had no further news to add from the last meeting. JB however, has been in contact with them re translating one of the educational binders into German as he was aware it had been translated into Swedish, he has had no positive response so far. This provoked discussion amongst the Board on what can be done to encourage more translations funded by the Industry.</p> <p><b>Genzyme</b> AM and EA had a TC with Genzyme about developing an educational program for nurses and other allied health professionals. Genzyme will respond EA as soon as funding of the project is clear.</p> <p><b>Low Bacterial Diet</b> AM provided an overview of the article/survey in EJONS along with the Cochrane Review which was still under way (independent from EBMT).</p>
<p><b>PR &amp; Strategic Plan</b></p>	<p><b>Membership</b> LP reported that the EBMT membership list contained the following NG members:</p> <ul style="list-style-type: none"> <li>• Individual NG Members: 46</li> <li>• NG members belonging to an EBMT centre: 528</li> <li>• All NG members: 574</li> </ul> <p>A problem for many NG members was identified: access to email and internet. AM suggested EA mention this at the main EBMT Board meeting. It was agreed to focus on informing the nurses that attended EBMT 2009 that they should approach their PI to check if they are listed correctly in the membership list. LP had contacted all EBMT centre PIs (534) requesting an update of their nurse member details – 23 responses had been received.</p> <p><b>AHPs</b> No AHPs listed so far – the Board agreed to remove item from agenda.</p> <p><b>NG Leaflet</b> LP reported that the leaflet had now been printed (1000 copies) and gave everybody an example to look at. Everybody agreed it looked good and although the colours were different the Board preferred the printed versions to the draft copy.</p> <p><b>Update EBMT Representations:</b></p> <p><b>DGHO</b> EA received an invitation to join and chair the DGHO Meeting in Vienna, October 11<sup>th</sup> – 13<sup>th</sup> 2008. EA accepted the invitation and will chair the session about BMT/SCT. <b>FEPI</b> No update received.</p> <p><b>Australian Group</b> AM had received a request from the Australian Group to use the low bacterial survey tool. The Board agreed this was OK as long as the EBMT were referenced/mentioned in any publication of results and that they provide any findings for the NG Newsletter.</p>

<b>Organisation</b>	<p><b>Election Process 2009</b> The call for new nominations should go out after EBMT 2009 in April in order to provide time to discuss/decide at the following December meeting.</p> <p><b>Goals</b> It was agreed that in December the Board will analyse the achievements of the Board and sub committees in order to discuss and agree goals for 2009.</p>	
<b>AOB</b>	No other items were discussed.	
<b>Next Meetings 2008</b>	Date: December 12th Time: 09.00-17.00 Location: Gothenburg	