



**EBMT Nurses' Group Board Meeting  
Friday 12<sup>th</sup> December 2008 Gothenburg**

**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

**Location:** Hotel Liseberg Heden, Gothenburg, Sweden

**Time:** 09:00-18:10

**Chair:** E. Aerts

**Welcome & Introduction**

EA commenced the meeting by welcoming everyone, thanking them for attending and providing a brief overview of the agenda.

<b>Agenda Item</b>	<b>Discussion</b>
<b>Previous Board Minutes &amp; Administrative Items</b>	<p>Minutes from the previous meeting were reviewed and agreed upon.</p> <p><b>Constitution &amp; Terms of Reference (TOR) from all committees.</b></p> <p>The Board reviewed the ultimate draft that Michelle had provided, it was agreed that Michelle would be responsible for making a note of the suggested changes and providing a final draft to agree on. There was some discussion about clarifying the definitions and terms used regarding types of membership available. The Board agreed to adhere and refer to the main EBMT's definitions.</p> <p>It was agreed that the final signed off version of the constitution and TOR will be sent to all National Group and committee chairs along with a summary of the minutes of this meeting in advance of the AGM in Gothenburg. Therefore comments/additions should be received within a week to finalise draft before the AGM.</p>
<b>Treasury Report</b>	<p><b>Report/08-090Budget/O'Donnell Fund</b></p> <p>JB will provide a fuller finalised report at the end of 2008 but in the meantime was able to confirm that 8,000€ was currently left over from 2008.</p>
<b>Research Committee</b>	<p>JB commented that his impression of the new RC is that it was working very well; minutes arrived quickly after TC/Meetings etc.</p> <p>Eva had summarised CVs following call for vacancies and had discussed with the group their preferences.</p>

	After discussion, the Board agreed to appoint Patrick Crombez to the Research Committee.	
<b>Communication &amp; Networking Committee</b>	<p>MD provided a brief overview of recent reports received from the CNC inc the website review.</p> <p>It was agreed that the newsletter would be sent to all non NG nurse members that attend the meeting in Gothenburg.</p> <p>The sponsoring of the newsletter that had been arranged by EA was discussed briefly; EA informed the board that Fiona McDonald would be drafting the invoices. The sponsors will pay the EBMT's main account and this would then be transferred to the NGs account.</p>	
<b>Exchange Visits/Travel Scholarships/Conference Travel Grants</b>	<p>MD confirmed that she had received one application from a nurse in Basel for the Educational Exchange Visit. She is interested in going to another similar unit in 2009 although the funding will come from the 2008 budget as the application will be counted in 2008.</p> <p>It was agreed that AM will use the National Groups to disseminate information about opportunities in 2009 to encourage more applications.</p> <p>Other methods of advertising discussed - to have a poster/flyer for Gothenburg and an article in the newsletter.</p>	
<b>Nuclear Accident Committee</b>	AM reported that Monica Fliedner had been unable to attend the meeting in Paris.	
<b>Late Effects</b>	<p>MD provided an overview of her attendance at the recent LEWP meeting in Paris. Prof. Tichelli (chair LEWP) was keen to continue the involvement and representation of the nurses group within the LEWP, however, this should be an interactive involvement. The previous agreement to add a nursing element to the 'Reduced Intensity Transplants/Quality of Life' 300 patient survey is to continue. The study already has ethical approval but it was agreed the NG could work to include the addition of sexuality questions even at this late stage. Some modules already in use could be used – MD to look into this further.</p> <p>MD suggested that the NG link person to the LEWP should ideally be a member of the NG Research Committee. It was agreed however to initially just include a board member for the next 12 months before introducing an RC member.</p> <p>Next LEWP meeting is on the Sunday before EBMT 2009.</p>	
<b>Outreach</b>	AM provided brief overview – EA keen to include more outreach nurses within the activities from the NG. It was agreed to add this item to next agenda and decide if it would be worth pursuing.	
<b>JACIE</b>	The Board reviewed Mairead's report to discuss whether or not it is still a valid point to pursue the objective of introducing nurse inspectors. Discussion regarding the benefits and drawbacks of this was raised but no decision made during meeting.	

<p><b>Setting up the Nurses Group Paediatric Committee</b></p>	<p>The Board reviewed the CVs received in application to join the new committee. Two applicants were successful and Erik will inform them. Discussion regarding the formation of the new committee was raised, the plan is to take it step by step and review progress at the next meeting.</p> <p>The question regarding the introduction of non EU members to committees was raised. This item will be added to the next agenda to discuss the above and possible NG Board link person.</p>
<p><b>National Groups Update (NGs)</b></p>	<p>AM confirmed that all NGs are invited to attend a meeting with the Board and provide a few slides for the National Groups Chairs Meeting so the information is more standardised, saves time and makes the conversation hopefully more clear. This means there is no report from each national group at the AGM</p> <p>France – discussion ongoing to become an official group  Turkey – EA and AM have had contact with two different persons. AM is trying to get them in contact with each other. It was agreed that a meeting in Gothenburg if possible would be beneficial.</p> <p>Nordic Forum – AM and EA had attended meeting in Iceland along with 80 people representing the various different Nordic country nurse groups. It was clear that all countries were different but all shared the same goal to create an EBMT Nordic NG. It was agreed they would get back to EA &amp; AM in the new year to once a decision had been made and who this would be arranged in practice, for instance a rotating chair between the countries.</p> <p>Michelle to do small presentation at conference to encourage and inform those interested in setting up a national group or forum.</p>
<p><b>Local Contact Nurses Guidelines (LCN)</b></p>	<p>The Board reviewed the current guidelines – it was agreed that the LCN guidelines should be introduced into the constitution as an appendix including rules and regulations.</p>
<p><b>Organisation</b></p>	<p><b>Report from EBMT Board</b>  EA reported that there wasn't any significant news from the EBMT's main board meeting in October. However, future EBMT meeting venues had been confirmed:</p> <p>EBMT Annual Meeting 2010: Vienna  EBMT Annual Meeting 2011: Paris  EBMT Annual Meeting 2012: Geneva</p> <p>The next meeting will take place in January 09 and EA requested that requests for items on the agenda should reach him in the 1<sup>st</sup> week of January 09.</p> <p><b>Lines of Communication</b>  The Board reviewed the flow chart provided by EA that will be attached to the constitution &amp; TOR.</p> <p><b>Structural Overview</b>  The Board reviewed the organigram provided by EA.</p> <p><b>Election Process</b>  The board discussed using an online voting system costing \$250 per 300 voters. It was agreed that further comparisons should be made to get the best deal. A decision needs to be made in April although the introduction of an online voting</p>

	system will be introduced to NG members.	
<b>Education Initiatives</b>	<p><b>Novartis</b> An advisory board meeting was held on October 4<sup>th</sup> about MDS. Nurses from the EBMT NG and the MDS Foundation participated in this meeting. AM and EA will inform about the next steps.</p> <p>On November 11<sup>th</sup> AM and EA attended the advisory board meeting on CML together with nurses, Novartis and patients advocates. Véronique Chapuis (Geneva) will write an article about this meeting for the next newsletter.</p> <p>EA and AM provided a brief update on the Novartis Survey: EA had made proposal for Education Initiatives project re CML and CLL. EA now working on 2<sup>nd</sup> draft to be sent to Novartis, EBMT NG Board, national group chairs and chairs of patients associations before Christmas 08 for feedback. Novartis will be looking into how it will be translated and financed.</p> <p><b>The 2<sup>nd</sup> ESH-EBMT Training Course for Physicians and Paediatric Nurses on HSCT in Children and Adolescents 2009</b> EA reported that they are still working on the 3<sup>rd</sup> draft – EA has provided input and will feedback to the Board as and when there is an update.</p> <p><b>NHL (Roche) Binder</b> EA has been asked to teach on a course – he will update the Board as and when.</p> <p><b>Celgene</b> EA attended a meeting on the 25<sup>th</sup> November with the director of Celgene – they would like official collaboration with the NG. Another meeting is set for the 19<sup>th</sup> of Dec to discuss how the collaboration with the nurses group will work and achieve and the next steps required.</p> <p><b>GENZYME</b> AM and EA are working on an educational project on stem cell mobilizing.</p> <p><b>GvHD DVD</b> AM reported that he had been in touch with the same group that produced his hospital DVD. They are able to set the DVD up online in the 4 different languages. This means the NG can place a link on the EBMT website that will take the viewer to the DVD online. It was agreed to move it forward –It was agreed a portion of the AMGEN money would be used to pay for this.</p> <p><b>ESH Handbook</b> AM contacted by Judith Raber (Mucositis expert) to update information about Mucositis and Mouth care provided in the handbook. AM believes that it is a good idea to involve the NG in providing input in this issue but also more in general.</p>	

<b>Scientific Committee Update</b>	<p>EA &amp; AM reported that there was no news since the last meeting, the last TC was cancelled..</p> <p>SC will have 2 vacancies after EBMT 2009 – the board took this opportunity to review the 6 EU applications to join the SC. It was agreed that the Board voted for each candidate and the 2 candidates with the most votes would be appointed. Inger Andersson and John Murray will join the SC after EBMT 2009</p>	
<b>EBMT 2009</b>	<p><b>3<sup>rd</sup> Patient &amp; Family Day</b> All appears to be organised – members of the Blood Cancer Society will be on hand to assist on the day (they speak English). Slides from speakers will only be shown in English and oral content in Swedish will be translated. EW &amp; IA confirmed they were happy with arrangements and content of the day.</p> <p><b>Pre Meeting Study Day</b> IA reported that the programme has now been finalised.</p> <p><b>Organisation &amp; Timetable</b> EA provided the first draft of the timetable for the whole period the NG would be involved during EBMT 2009. The Board reviewed it and amendments/additions should be added to a copy EA will send to Board. JB suggested that board members add details of meeting and presentation they will be attending.</p> <p><b>National Groups</b> Meetings for those not involved with a National Group have been arranged to take place on Monday at 17:30. EA has arranged flags/signs that will be hung in main hall.</p> <p><b>National Groups Chairs Meeting</b> Monday 12.30-13.30 – EA asked Board to look out for lunch bags to ensure all chairs are provided with lunch during the meeting.</p> <p><b>AGM</b> Tuesday 12:30-13:30 EA reminded NG Board link persons to approach committee chairs for report and slides (5 mins per chair).</p> <p><b>Meeting with Committee</b> All committee chairs have been contacted and approached re meeting times/room etc.</p> <p><b>Best Abstract/Best Poster</b> Organised.</p> <p>EA confirmed that after receiving a call from AKM, the conference organisers would now be referred to as Congrex.</p> <p><b>25<sup>th</sup> Anniversary Reception (1 hour)</b> EA also confirmed that those officially involved in arranging the NG's 25<sup>th</sup> Anniversary celebrations would be:</p> <ul style="list-style-type: none"> <li>• Interel via Viropharma</li> <li>• AKM (organising reception )</li> </ul>	

	<ul style="list-style-type: none"> <li>• EBMT Executive Board</li> <li>• EBMT NG Board</li> </ul> <p>MD has drafted invitation letter to reception and forwarded to AKM – EBMT NG Board will send this out in mid January. Mailing list to be confirmed.</p> <p><b>Entertainment</b> EW &amp; IA are arranging live music for the event.</p>	
<b>EBMT 2010 - Vienna</b>	<p>Brigit Keinrath from the Austrian NG National Group will be the local nurse for 2010.</p> <p>It was agreed that the sponsor meeting will be discussed after EBMT 2009 in April, EA and AM will provide a draft before the next board meeting.</p>	
<b>PR/Strategic Plan</b>	<p><b>Membership</b> LP confirmed number of total NG members and then provided a breakdown of individual NG membership numbers. These numbers would change significantly after January when the annual membership modifications had taken place. In addition, individual NG members were in the process of renewing their application which would mean numbers of members would also be affected.</p>	
<b>EBMT NG Goals 2009</b>	<p>EA asked the board to think about what we want to achieve mid long term – he suggested also asking committee chairs for input. It was agreed that these goals should be added to the strategy paper so they can be linked together.</p>	
<b>Next Meetings</b>	<p>The Board discussed suitable dates and locations for the next set of meetings in 2009 – see timetable below:</p>	