

## **A G E N D A**

### **5<sup>th</sup> Parents' Organisation Meeting Freising, Germany**

**Friday, November 26 - Sunday, November 28, 2010**

#### **Friday November 26, 2010**

Participants to arrive until 12 a.m.

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|-------------|--|
| 12:00       | Lunch at the Hotel   |
| 13:00       | Welcome and short introduction for new participants<br><br>Short review of the national activities after the launch of<br>the Benchmarking Report in Brussels and Prematurity<br>Awareness Day |
| 14:30-15:00 | Coffee break   |
| 15:00-16:30 | Presentation of March of Dimes "Parent – Support – System" in the USA<br>(telephone conference with Judi Gooding, Liza Gene Cooper, Phyllis Williams-<br>Thompson / White Plains, NY)          |
| 16:30-17:30 | Discussions  |
| 17:30       | Free at your disposal/ Christmas Market in Freising  |

## **Saturday November 27, 2010**

8:30 - 10:30	<p>Review/ Current situation by EFCNI</p> <ul style="list-style-type: none"> <li>• „Prematurity Awareness Day 2010“</li> <li>• EU Advocacy and Policy (Benchmarking report, WHO, Meetings with ECCF or EU Commission)</li> <li>• Global Alliance</li> <li>• Outlook</li> </ul>
10:30 - 11:00	Coffee break
11:00 - 12:00	<p>Presentation on the social medical after care system called“ Bunter Kreis” (Coloured Circle) German certificated after care programme for preterm infants and children with illness (Dr. Antje Otto/Munich, Germany)</p> <p>Discussion about implementation or development of such or similar projects on a national base</p>
12:30	Lunch break
13:30 - 16:00	<p>Presentation “NIDCAP- Newborn Individualised Developmental Care and Assessment Programme” (Jacques Sizun, MD Medical Director and NIDCAP Center Medical Director/ Brest, France)</p> <p>Discussion about how can we work together, building networks and support to have more NIDCAP centers in Europe</p>
16:00	Coffee break
16:30 - 18:00	<p>Working groups</p> <p>Preparing a national declaration paper / Preparing a national position paper (prevention, quality standards, after care)</p> <p>Set-up of a new parents’ organisation</p>
19:30 Open End	<p>Bavarian Evening at the Stub´n of the Marriott Hotel .....</p>

**Sunday, November 28, 2010**

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|--------------|--|
| 9:00 - 12:00 | Election "Parent Advisory Board" of EFCNI<br>- Suggestion from EFCNI to discuss:<br>3 Members + 1 Substitute (one small, one big and one East European country, each country who will participate in this meeting will have one voice, etc.) |
| 10:30        | Short coffee break<br><br>Wrap-up presentations working groups   |

EFCNI will collect all information of these workshops. We will give every group an information package shortly after the meeting. The material will help you to share the information with your colleagues and maybe professional board members of your national or regional organisation. Please finalize the documents together with your national team. The papers will strengthen your position for advocacy and policy work in your country.

Having such papers is an important step in our advocacy and policy work. WHO has offered us to work together on a national level as well. To start collaboration, they would need a declaration and position papers..

If you already have national position papers or declarations, please bring these along with you to the meeting!

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| 12:00 | Optional lunch |
| 13:00 | Departure      |

### **More information about the election discussions:**

- Election of three representatives for the EFCNI “Parent Advisory Board”  
The elected members should represent:
  - small country
  - big country
  - eastern country

*When thinking about nominating a person for the election, please take into consideration that he/ she should be in a position to meet certain requirements:*

*The representative would need time to attend the annual board meeting in Munich and also some events in Brussels throughout the year (travel costs will be covered). He/ she would need 5 – 10 hours per month for conceptual work and should be available for regular email exchange/ feedback.*

*The elected members would need to represent the interests of all associations in a neutral way.*

Points to be discussed in Freising prior to the election:

- Length of an election period (two years or more?)
- Should there be a possibility for re-election?
- How many times should a member be re-elected?
- etc.

### **Issues, we should also discuss in Freising:**

- More focus on prevention of preterm birth
- Health insurances excluding preterm infants
- Support of new parents' associations (tutorial system)
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