



## Executive Committee Teleconference Minutes February 20, 2006

Present: Mike Harlos, Filomena Nalewajek, Maria Rugg, Kim Widger and Greg Adams (notetaker)  
Absent: Honna Janes-Hodder, Roberta Woodgate, and Sharon Baxter,

### 1. Call to Order and Welcome

Mike called the meeting to order.

### 2. Review of the Agenda

Two items were added to the agenda under Other New Business (Section 7)

7.3 Status of pediatric hospices in Canada

7.4 Member from Quebec

### 3. Approval of Minutes – September 7th, 2005

Committee members did not have copies of the minutes of September 7<sup>th</sup>, 2005. Greg will re-send the minutes for approval at the next teleconference.

### 4. New Business

#### 4.1 Guest: Meaghan Fletcher & Harvey Bosma

Fil introduced Meaghan and Harvey to the Committee. Meaghan is a Social Worker who has worked at Canuck Place for a number of years and has taken a leave of absence to pursue a PhD. Harvey Bosma is a Social Worker at UBC. Meaghan and Harvey have come before the CNPCC Executive Committee to ask for assistance with a research project. Meaghan and Harvey are working with a NET team at Vancouver's children's hospital and Canuck Place. The purpose of their research is to identify research priorities for pediatric hospice palliative care using a Delphi process. Through their research they are hoping to put together a panel of experts to build a consensus of opinion. The majority of this work will be done by e-mail. Meaghan and Harvey are hoping that the CNPCC and CHPCA will be able to assist with their search for experts to be a part of this research project. Meaghan and Harvey will send particulars and information about the study to Greg and Mike.

#### 4.2 The Executive discussed this request and agreed to provide the following support:

- Mike will post information and the invitation on the CNPCC web site
- Greg will attach the information and invitation to the minutes of today's teleconference
- Greg will disseminate the information to the CHPCA List Serves and the Monthly Update e-mail list.

4.3 Kim Widger expressed interest in being a part of this project. The Executive expressed interest in hearing an update on the status of this project at a later date. Meaghan and Harvey agreed to provide an update. Kim agreed to act as a liaison with Meaghan and Harvey and will invite them to speak to the Executive when appropriate.

### 5. Business Arising from the Minutes

### 5.1 CNPCC Annual Meeting in Edmonton – Debrief

Overall the comments regarding the success of the CNPCC meeting in Edmonton were positive. Everyone present appreciated the presentation by Fil, and were equally pleased with the announcement from Health Canada regarding the funding of the Pediatric Norms Consultation Process. Fil asked Greg to check the CHPCA files as she thought there were evaluation forms present for the meeting. The one disappointing aspect was that there were only about 20 people present for the meeting. Greg reported that the CHPCA will attempt to address this for the next conference.

### 5.2 Pediatric Norms Consultation – Update

Greg provided an update on the norms process. To date there have been 65 surveys completed. A cursory view of the analysis indicates that a majority of respondents selected “Agree” or “Strongly Agree” for all of the norms and principles. The majority of respondents have been from Ontario and BC. All other provinces are represented with the exception of New Brunswick and Saskatchewan. The deadline for completing the survey is Thurs. Feb. 23<sup>rd</sup>. Maria agreed to contact Susan Fowler-Kerry in Saskatchewan and will encourage her to complete the survey as well as encourage others in Saskatchewan to complete the survey. Greg will send an e-mail to contacts in New Brunswick to encourage them to complete the survey.

Next Steps: Once the deadline has passed the data will be sent to the writer hired by CHPCA to complete the writing/editing of the Pediatric Norms. Once she has completed the document it will be translated into French. When both documents are ready the CNPCC and CHPCA will need to develop a dissemination strategy.

## 6. Working Groups Update

### 6.1 Research Update

Kim Widger reported that a Call for Master’s and PhD students to join the Pediatric Palliative Care New Emerging Team has been issued and the deadline for responses was last week. As Kim is now finished her maternity leave she will be able to provide a more detailed report at the next teleconference. It was confirmed that Mike has included a hyperlink to the NET Grants web pages in the Research section on the CNPCC web site.

### 6.2 Pediatric Survey Update

Fil reported that nothing further has been done with the national survey data since the presentation at the CNPCC annual meeting in September. The Executive agreed that the data needs to be further analysed with the hope of writing journal articles base on the results of the survey. Kim and Maria offered to assist with the detailed analysis of the survey data. Greg will send copies of the raw data to both Kim and Maria. Fil will send a copy of her presentation in Edmonton to Kim and Maria. Maria and Fill will collaborate to look for additional funding to assist with this work.

### 6.3 Education Update

Maria reported that she is trying to connect with the EFPPEC project. She is hoping to submit an abstract to their Symposium in April regarding pediatric hospice palliative care. She feels confident that her proposal will work with the goals of the project. Her proposal will look at building a national interdisciplinary curriculum for pediatric hospice palliative care.

## 7. Other New Business

7.1 The Pallium Project and the pediatric component of the updated 99 Questions palliative care resource book (Maria)

Maria reported on the progress of this project. For those that are not familiar with the resource, it is a reference book that was developed by a group in Alberta for use in the field. The book contained 99 brief questions and answers to help guide practice. The Pallium Project has funded a project to convert this local tool into a national tool. Sick Kids Hospital in Toronto was asked to be a part of the review team. Their role was to ensure that pediatrics was included in the new national resource. In the end, despite a number of conversations Maria held with Michael Ahern and The Pallium Project, it was decided that since pediatric hospice palliative care was not applicable to enough people, it would not be included in the new resource. The Pallium Project did say that they would consider creating a companion document for pediatric hospice palliative care at a later date. Maria reported that she felt very frustrated by the process and expressed concern about excluding pediatrics from the updated resource.

7.2 CCHSA Accreditation Process (Fil) – Tabled until the next teleconference

7.3 Status of pediatric hospices in Canada (Fil) - Tabled until the next teleconference

7.4 Member from Quebec – Discussion – Tabled until the next teleconference

**8. Next Teleconference Date and Time**

The CHPCA office will send out an e-mail to determine the date and time of the next teleconference.

**9. Adjournment.**