

**CNPCC Interest Group Meeting  
CHPCA National Conference in Winnipeg, Manitoba  
Sunday, October 19, 2009**

***Present at Meeting:***

Mike Harlos	Filomena Nalewajek	Grace MacConnell
Lillian Rallison	Marie-Claude Gregoire	Simone Stenekes
Marli Roberstson	Rawabi Sharikh	Betty Davies
Susan Cadell	Hal Siden	Lynn Straatman
Rose Steele	Kathy Wilson	Peggy Freymond
Lisa Perlman	Lynn Grandmaison Dumond	Marion Rattray
Chris Hohl	Nichole Austin	Gail Andrews
Isabelle Cabot	Anne Jones	

**1. Welcome and Introductions**

Mike and Fil co-chairing meeting. Attendees provided introductions

**2. Background Info – Brief Background of the history of CNPCC, goals and functions, website**

Fil provided information about the history. In 1999 there was a realization that networking amongst pediatric palliative care practitioners was needed. Gerri Frager, Fil Nalewajek, Stephen Liben and Maria Rugg had a phone call and became an interest committee for pediatric palliative care.

In 2002/2003 the CHPCA was involved and the committee became a formal interest group under the CHPCA structure. The first terms of reference were developed. A website was developed by Mike Harlos (<http://cnpcc.ca>) which includes CNPCC information and links to many resources. A couple research studies determined that there was no uniformity to practice. Therefore, feedback was obtained nationally, and Norms of Practice for Pediatric Palliative Care were developed. A CNPCC newsletter is sent out approximately 3 times each year.

The goals of the CNPCC are to move the pediatric palliative care agenda forward, lobby government, provide a connection for those across the country and also encourage the development of research.

The CNPCC Executive Committee meets every 2 months.

**3. Changes in the CNPCC Executive**

There are several changes to the CNPCC Executive that are taking place. Fil (Vancouver) is leaving as co-chair. As well, Sharon Spicer (Calgary) and Michèle Viau-Chagnon will be stepping down.

Joining the executive are Marie-Claude Gregoire (Halifax), Marli Robertson (Calgary), Hal Siden (Vancouver), Stephen Liben (Montreal) and Simone Stenekes (Winnipeg) as co-chair.

The individuals remaining on the executive are: Maria Rugg (Toronto), Dawn Davies (Edmonton), Roberta Woodgate (Winnipeg), Kim Widger (Toronto), Liz ?? (Montreal??), and Mike Harlos (Winnipeg) as co-chair.

Mike made special mention of Fil's contribution as co-chair, and recognized the efforts she has made to this work since the inception of the CNPCC.

#### **4. Canadian Network of Pediatric Hospices**

This is a network of pediatric hospices that meets by teleconference for the purpose of sharing information and resources and supporting each other in their work. The intent was to standardize aspects of hospice development and to eventually develop standards of care. This network reports to the CNPCC.

#### **5. Discussions about where we are and what we'd like to see develop with: Education/Training, Research and Administration/Advocacy/Policy & Procedure**

##### **Education/Training**

Discussions included the need to establish national competencies for different disciplines, agree on competencies, and develop modules for teaching. The training of physicians was highlighted as being important, but then the need to consider interprofessional education was brought forth. There may be core competencies for certain disciplines and then multidisciplinary competencies. Suggestion was made not to focus on physician fellowships, as that is a different level of education.

The need to have some idea of what people are currently doing and whom they are educating is important to consider before developing any type of curriculum. Another idea brought forth was to form an ad hoc group and survey what is happening and what has been successful and what has not.

It was mentioned that a strategic plan needs to be put forward by the Executive, as education is likely the biggest priority for the CNPCC.

Also the idea of education those outside of pediatric palliative care was brought up. Suggestions included presenting at non-palliative care meetings and conferences and going to specific sub-specialty meetings in order to increase the awareness of pediatric palliative care. Also a suggestion to put information about the CNPCC and pediatric palliative care into other specialty newsletters to increase awareness. We need to broaden our reach and cast out net to explain who we are, what we are doing and the resources that are available.

**ACTIONS:** (1) Have the Executive further evaluate education and training issues.

(2) Develop a short description of the CNPCC - who we are, what we do and how we can help.

### **Research**

We need to have a sense of what is happening and share the information on the CNPCC website. This is a good way of disseminating the research into practice. Also a suggestion that came forward was to have one issue of the CNPCC newsletter per year highlight research that is in progress or has been completed.

### **Administration/Advocacy/Policy & Procedures**

Three specific issues were brought forth during this discussion:

- 1) The role of CNPCC in lobbying for in home and out of home respite care. The need to define respite and consider how respite may be needed for palliative care patients.
- 2) Education about palliative care, that others understand it is a philosophy and not a place or “beds”.
- 3) Transitioning to adulthood. The adult world may see these patients as chronically ill and not palliative.