



**Executive Committee Teleconference
Wednesday, October 1st, 2008
2:00 p.m. (Eastern)**

Minutes

Present: Mike Harlos, Michèle Viau-Chagnon, Dawn Davies, Sharron Spicer, Maria Rugg, Filomena Nalewajek, Greg Adams (staff) Gillian (Staff & Notetaker)

Absent: Kim Widger
Roberta Woodgate

1. Call to Order

Mike called the meeting to order.

2. Planning of the CNPCC Interest Group meeting in P.E.I. (Agenda)

- Greg discussed including the on line pediatric resource commons on the agenda. This would include about a 10 minute discussion to the group. There could be a couple of power points with screen shots to show everyone how it will look on the CHPCA and CNPCC website. The bilingual pediatric resource flyer will also be give out to the participants
- Greg will also discuss the work CHPCA did with the English translation of the Quebec pediatric standards
- CHPCA will bring some paper copies of the Quebec standards along with some CD copies of the Pediatric Norms
- Agenda then should proceed to cover the priority areas. These were discussed at the last meeting and were covered in the September 11th minutes. They have been pulled from the last meeting – please find below
 - If the group look at the priorities that were presented at last years conference and work from those issues, that will lead to the next steps.
 - CNPCC could look at priorities that have been covered – profile them and what dissemination has taken place
 - How have CNPCC worked with the general public, schools and education
 - Core competencies are an evolving issue right now, trying to work on similar issues with people who want more education in pediatric care.
- When discussing the agenda the group talked about discussing how the CNPCC worked with the general public and schools
- The CNPCC were unsure of what the priorities were, Greg was asked to resend them and put in some of the action items.
- It was asked if we knew any demographic information about where all the participants are coming from.

- CHPCA does not have this type of information on the registrants but we may ask what their discipline area is.
- This may be worked into the agenda, it was said that it may be valuable to know and to ask the group where they are coming from, if they have a CNPCC background and how they can be connected to the CNPCC.
- The CNPCC website can then be explained

Agenda Draft

Background Info/Welcome

Actions over the last year

Main goals, focus

Pediatric Norms (Greg)

Quebec Standards (Greg)

Sub Committees – Pediatric Senior Members of the Canadian Hospices

Priorities

Next Steps/Discussion/Question: Where do you see CNPCC going?

- Mike asked for the minutes from after February 7th
- Greg will send them to Mike

3. Pediatric Resource Commons Project – Update (Greg)

- The text for the pediatric resource commons that will be used on the CHPCA website has been approved and is in the process of being designed.
- The CHPCA will try to put in some of the resources that we know about into the pediatric resource commons
- Bilingual pediatric resource commons flyers have been designed and will be put in the CHPCA conference bags. There will also be some copies at the CNPCC interest group meeting.

4. Grant Application

- CHPCA's project meeting was cancelled, therefore the grant application was not addressed at this particular time
- Grant application will be discussed at next project meeting in the middle of October
- CHPCA will be willing to do a first draft of the letter that is needed for the grant application
- Maria mentioned that when she spoke to the person involved they said they are looking for a compelling case. They are not really looking to fund any more this year but to at least do up a one page document that will capture the main points of CNPCC's focus and what they have contributed
- The other highlight is to talk about how the grant given to CNPCC will affect children's health and the idea that it is national.
- There is a need to speak to the impact of what we are working on right now and what the potential it is to be with these types of resources.

5. Research Discussion

• Update on Montreal Conference

- At the Montreal conference Fil and others met with the senior staff from the five pediatric hospices in Canada
- List of participants were
 - Lloyd Cowin, Roger's House
 - Filomena Nalewajek, Canuck Place Children's Hospice
 - Rauni Salminer, Philip Aziz Centre
 - Deb Sloan, The Darling Home for Kids
 - Marti Robertson, Calgary Flames House
 - Anne Connelly, Roger's House
 - Marie-Josée Dubois, Nicole Marcil-Gratton, Michèle Viau-Chagnon, Lyse Lussier, Maison André-Gratton
 - Manon Champagne, UQAT Rouyn-Noranda
 - Mona Turdel, Suzanne Mongeau, Université du Québec à Montréal

The group talked about common issues

- Some of the questions that came out of the meeting were the relationship between the group and CNPCC.
- The group identified that they would like some official status, possible be recognized at the sub committee.
- This would ensure good communication and representation.
- Some of the members from this group could sit on a sub committee, CNPCC may be like the umbrella group.
- It was agreed from all that this sounded very interesting and that it would be a good way to communicate. The information regarding the sub committee could be accessed from the CNPCC website where they could share policies and meetings
- There would have to be some controls in place to make sure that there is no overlapping of information between all the sites
- It was suggested that it would be nice to announce that there would be an official sub committee on the next newsletter or website
- A Terms of Reference would need to be done up for the sub committee
- Greg brought up the question of whether or not this sub committee would be looking for finances. Is there a commitment from them so that they may internally support each other
- CNPCC needs to decide about items such as how many times the subcommittee would meet, would they only be meeting by email etc. It was thought that they would probably on do teleconferences about 3 times a year
- Greg will check with Sharon Baxter to see if there is any financial support for more teleconferences
- Fil is to put together something about what the sub committee expectations are and email to Greg
- Fil asked if Mike to add to the Agenda for the Ped's interest group meeting

6. Pallium Funding

- Mike was given a grant from Michael Aherne (Pallium) in the amount of \$20,000. It was funding to work further on building a capacity. Books were developed and \$7,000 was spent. The remaining \$13,000 went back to Michael Aherne (Pallium) but Pallium would still like to make the remainder of the money available to initiatives with a pediatric palliative care focus
- There is a repeated request for education from various disciplines, but it is not known how to help them.
- It would be nice if the grant money could go towards establishing a national consensus on core competencies in pediatric palliative care.
- For example – if someone wanted to shadow a doctor and they only could spend 2-4 weeks with them, the norms would outline what is expected of them within that timeframe
- If someone was with them for a year, the outline would again explain what should be covered in that time frame.
- It was brought to attention that it should be discipline specific. If it were interprofessional it would be a huge endeavor for \$13,000. You would need grants in the \$100,000 range
- Fil mentioned that you can have core concepts but the competencies need to be for each separate profession. For example, nurses need to write competencies through an exam.
- Core concepts can take a very long time, EFFPEC was a 5 year project that developed core competencies just for physicians
- Fil talked about sharing information with trainees, you could have nurses who could shadow for a day
- The grant could possibly be used to put together a guide on training initiatives, decide what is the most important strategies. What tools will the learners need to do things in a certain time frame. This may be especially important for when you have residencies coming through
- Mike will discuss further with Michael Aherne, possible in PEI. It may be possible to do a survey first to see what is needed, then gather the information and make a little toolkit with guidelines or learning objectives. Once the issues are agreed upon you could approach the local groups and say as a national group we feel this is a priority.
- The definition and key components can also be looked at and then move forward.
- Many years ago Neil MacDonald put together a little pamphlet; it was to guide any education in palliative care. This little booklet was carried around and you knew you had guidelines to help with education
- Fil asked the group if anyone had done an IPPC 2 day workshop. Maria had said she had done one and that is was good for people who were inexperienced with pediatric palliative care. It also depends on who is brought in as a speaker
- Greg to review grant application with Sharon at CHPCA project meeting in early October

7. Action Items

- Mike to draft agenda for the interest group meeting at the CHPCA conference
- Greg to send group copies of the priorities add in some action items
- Greg to send final copies of minutes since after February 07
- Fil to put together something about the expectations of the sub committee and send to Greg
- Greg will then approach Sharon to see if any funding for teleconferences
- Fil to put together something regarding the Pallium funding, send to Mike.
- Mike to possible add the Pallium funding onto the agenda, for the CHPCA conference
- Mike to discuss further funding with Michael Aherne when in PEI
- Grant application to be discussed at CHPCA project meeting

8. Next Teleconference

- To be determined

9. Adjournment