

TELECONFERENCE
CANADIAN NETWORK OF PEDIATRIC HOSPICES
January 25, 2013

Present: Janet McFarlane – Rotary Flames House in Calgary (Chair),
Dr. Marli Robertson – Rotary Flames House in Calgary,
Rauni Salminen – Philip Aziz Centre in Toronto,
Tanice Miller – Canuck Place in Vancouver,
Margaret McNeil – Canuck Place in Vancouver,
Lloyd Cowin, Roger’s House in Ottawa
Lyse Lussier – Phare-Lighthouse in Montreal
Anna Cooper – Bayshore Home Health in Mississauga, Ontario
Laureen Nickerson – CHPCA in Ottawa,
Kristin Horrell - Darling Home for Kids in Milton, Ontario
Penny Dew – Canuck Place in Vancouver (Minute Taker)

Guest: Michelle Dowling in Ottawa

Regrets: Kathryn DaSilva – Rotary Flames House in Calgary
Joanne Gallevo – Philip Aziz Centre in Toronto

(1) Welcome

The Chair, Janet McFarlane, welcomed guest Michelle Dowling to the meeting. Michelle is working on her MBA from McMaster University and is currently an administrative resident at Roger’s House.

(2) Approval of Agenda

The Agenda was approved.

(3) Approval of Minutes of November 23, 2012

The Minutes were reviewed and approved.

(4) Standing Items Brought Forward

4.1 Preface to Core components for Pediatric Hospice

Deferred.

4.2 Palliative Care Week

Rauni is working with Ian Brown of the Globe and Mail to write a piece on all hospices for Palliative Care Week in May. She will get back to the group with the details

4.3 CNPCC Update

Meeting will be held on January 30th. Marli to take some items from this meeting to CNPCC.

4.4 Terms of Reference – Review

Deferred.

(5) Other Business - Visiting Volunteer in the Home Program and Day Program

Michelle Dowling was again introduced to the network members. She is:

- investigating the feasibility of running a Volunteer Visiting Hospice Program out of Roger's House. Volunteers would go to patients' homes for a few hours a week to help out.
- Investigating the feasibility of a Day Program at Roger's House during summer holidays or other breaks from school.
- Conducting a Root Cause Analysis of medication errors at Roger's House.

She spoke about the volunteer pilot project program currently underway at Canuck Place to incorporate volunteers into children's homes to provide practical and emotional support. The CPCH volunteers do not provide direct care of the child as they are not skilled/trained to do so, but they do lend support to the family and siblings.

There are risks and concerns associated with volunteers in the home. Roger's House is looking at whether it would be feasible and the amount of resources that would be required.

Provision of a "day program" within the hospice was also discussed. It would include the same services that are currently offered except the children arrive in the morning and leave in the evening. It was noted it is needed and used by families when there is no school, on weekends or during July and August. The families who live closer to the hospice will use it more as it takes time and effort to pack up the child and drive to and from the hospice.

***Action:** Michelle will email each CNPH member with a description of the Roger's House initiatives; members to identify persons for Michelle to contact.*

5.1 Role Clarity – CHPCA/CNPH/CNPCC (remains on Agenda)

<http://www.icpcn.org.uk/>

<http://www.togetherforshortlives.org.uk/>

5.2 Information Sharing Format

***How can we make involvement in CNPH meaningful in our work?
What do we really want to be doing when we meet?***

Discussion occurred amongst members with the conclusion that there are specific issues that members would like to learn from each other and specific areas of expertise that members can share with each other.

Examples of areas to explore with one another:

1. New initiatives and new programming
2. Learn about how to build partnerships with one another. National level of partnerships and how to build partnerships with hospitals and community. One can look at partnerships in fundraising or service delivery.
3. Community of Practice model
4. Service tension points within the hospice and service tension points between the organization and external partnerships. Develop standard/process guideline that would make a difference going forward (specifically around sharing knowledge)
5. Clinical Expertise Areas: Examples: Symptom management, root cause analysis of medication errors, compassion fatigue.
6. Partnership with CAPC - Identify which national organizations take a piece so duplication is eliminated.

Examples of areas of expertise or unique contributions to share:

1. Rotary Flames House – bereavement and consultation teams. They developed a consultation team and bereavement support program long before the hospice came to fruition.
2. The Darling Home for Kids - has an excellent residential program.
3. Canuck Place - research and information on recent population/epidemiological studies to share; work being done in BC to develop a provincial pediatric palliative care service framework throughout the province.

Actions:

1. *Group decided to meet once per month, for one hour duration.*
2. *Each member to send list of areas where their organization has specific knowledge or expertise to share and to identify any specific topics or areas of practice where they are interested in learning more from others. Send topics to Janet McFarlane by February 1st and she will create a list and identify the major common topics for discussion at the next meeting.*
3. *One topic (or two) to be identified for each meeting and members will come prepared to discuss.*
4. *Members to ask the appropriate staff to attend for a particular topic.*

5. *Anna Cooper to check into securing a conferencing line, once a month for one hour, 8 months of the year, using "GOTOMEETING" or "SKYPE" or "WEBEX". It does not need to be with the camera option. New service line to commence with the March meeting. Janet will send out instructions to everyone after the email is generated.*

There being no further business the meeting was adjourned at 2:07 p.m. EST

The next meeting is scheduled for March 22, 2013 at 1:00 p.m. EST via Teleconference (service to be determined)