

Canadian Network of Pediatric Hospices (CNPH)
Retreat Minutes: Thursday February 24th 2011

| Agenda Item | | Action |
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| Welcome & Introductions | <ul style="list-style-type: none"> Round table introductions Morning meditation hosted by Marcel Leffelaar, to facilitate mindfulness and grounding. (This is a once/week practice during our RFH clinical rounds) Lloyd advised the group of an opportunity to have a feature on pediatric hospice palliative care in 'The Globe & Mail' with reporter Carly Weeks. | Lloyd will email the info out to the group. |
| Approval of Agenda | <ul style="list-style-type: none"> Agenda approved as presented | |
| Terms of Reference | <ul style="list-style-type: none"> Reviewed & edited See attached TOR | |
| Network Function prioritization and action plans: | <p>Functions:</p> <ol style="list-style-type: none"> Develop guidelines for establishing a pediatric residential hospice, utilizing existing norms of practice and emerging standards of care. <ul style="list-style-type: none"> Acknowledgement from the group that there are valuable existing documents to support this work. These include: 1) Creating a Healing and caring environment at End Of Life (Fraser Health), 2) Accreditation Canada Hospice, Palliative and End of Life Standards, 3) Quebec Standards of Practice for Pediatric Palliative Care, 4) Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice (CHPCA), 5) Implementation Manual; Establishing Hospice Programs for Children and their Families (CHIPPS). The group agreed the resources would guide our development of pediatric residential hospice core components Sharing information on pediatric residential hospices for the CNPCA website <ul style="list-style-type: none"> Work with Mike, CHPCA, to develop a process for this function Develop various categories of information for website development Some category suggestions: research, education, resources and materials (suggestion to post various documents, papers, etc that the various hospices have developed or published), administrative (funding, governance policies, models), volunteers (orientation/training), resources for clinical providers, clinical tools, acuity scales patient advocacy family, therapeutic boundaries (for staff/volunteers) & history/evolution/development. Suggestion to post the World Palliative Care Organization Report looking at national research stats and information Information on the website can be reviewed annually prior to network's yearly face-face meeting, to ensure everything is kept accurate and up to date Lobbying - creating a position statement; Canadian | Marli has offered to be the central contact for Mike and will connect with him to advise that group's plan and develop a process to provide him with info for the website. |



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| | <p>research literature/data “Serving Canada’s Children” – Croft & Killan’s</p> <ul style="list-style-type: none"> • <i>Current resources to post:</i> family advisory committee information, Terms of Reference of CNPH, governance/board documents, therapeutic boundaries, RFH bereavement resource list, publications that the various hospices have developed or published, acuity scales, family satisfaction/evaluation surveys, criteria for intake, family handbooks. <p>3. Educate and increase awareness about pediatric residential hospice care. National strategies discussed:</p> <ul style="list-style-type: none"> • Globe & Mail Article (as above) • Consider ways to get involved in annual local or provincial events; such as the “National Hike for Hospices”, etc... • Participation in annual national or government level events • CHPAC annual conference – have a poster or booth set up in the exhibition hall • Kathryn & Janet have sent in an abstract – Living on the edge: Palliative Care for Neonates to the 2011 CHPCA Conference. Would like to have a panel comprised of representatives from the CNPH. • Suggestion to try to get a national TV spot on ‘National Hockey Day’: Supported by our NHL connections/partners • Attendance/presentation at CAPHC Conference • Palliative Care Week – advocating for a pediatric focus <p>4. Advocate for the provision of pediatric residential hospices</p> <ul style="list-style-type: none"> • Looking at national strategies to obtain funding support • Government – Connecting with the Senate e.g. inviting government officials for a tour of our pediatric residential hospices • Lobbying – advocating for a vision of hospice in every province. Looking at the research (articles from Australia & England) re: How many palliative beds per population is adequate. Staff educating public/government. • Elaine Orrbine, CAPHC, has advised she would be willing to assist with data collection, looking at standards, offered a platform for pulling together resources that support a national pediatric palliative & hospice care picture and developing some knowledge transfer ideas. • Suggestion to invite Elaine to attend the next meeting to discuss how work of CAPHC can support the work of the network • Filomenia and Tanis shared that Canuck Place is currently developing a database that will.... (need clarification) • Please bring an inventory of the various data collected at your respective Hospices to the next meeting. | <p>Llyod & Filomenia</p> <p>Filomenia will connect with Sharon Baxter.</p> |
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Canadian Network of Pediatric Hospices

Terms of Reference

Purpose:

The Canadian Network of Pediatric Hospices (CNPH) fosters collaboration and sharing among pediatric residential hospices in Canada. The network provides leadership about pediatric palliative care to residential hospice settings.

Membership:

All pediatric residential hospices in Canada that have registered charity status and a Board of Directors and/or provincial health funding are eligible to participate as members. CHPCA will participate as an observer. CNPH will include others as observers from time to time. The committee will elect/acclaim a chair on a 2 yr term. The chair will also be the representative in the CNPPC committee.

Meeting frequency:

There will be a minimum of four meetings per year.

Quorum:

CNPH requires minimum attendance of 50% of the membership +1 for decision making. Meetings can be held without quorum for discussion purposes.

Functions:

1. Develop guidelines for establishing a pediatric residential hospice, utilizing existing norms of practice and emerging standards of care.
2. Sharing information on pediatric residential hospices for the CNPCC website.
3. Educate and increase awareness about pediatric residential hospice care.
4. Advocate for the provision of pediatric residential hospices.

Reporting:

CNPH operates as a standing sub-committee of the Canadian Network of Palliative Care for Children (CNPCC), under Canadian Hospice Palliative Care Association (CHPCA).

Recording of minutes will be shared among the members. Approved minutes will be distributed to all members, observers, CNPCC and CHPCA and on the CNPCC website.