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Team for Research with Children and Adolescents in Palliation and Grief (TRAC-PG)



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Welcome to our Winter 2008 Newsletter (Second Edition)

What's New with TRAC-PG:

Highlights from the CHPCA Conference 2007

Meetings of the Canadian Network of Pediatric Palliative Care (www.cnpcc.ca) and the PedPal Net (www.pallpedsnets.ca/) were for me and many others, the highlight of this year's Canadian Hospice Palliative Care Conference (CHPCA November 2007). The meetings hosted by Mike Harlos and Fil Nalewajek, CNPCC and by Hal Siden, PedsPalNet, launched the 17th Annual CHPCA Conference, "Hospice Palliative Care: At a Crossroads" with a 3/4 day of business, networking, information sharing and research all with a focus on children and their families. The newly developed document "Pediatric Hospice Palliative Care, Guiding Principles and Norms of Practice", a collaborative initiative between the CHPCA, CNPCC and several national pediatric palliative care programs was publicly announced and distributed at the meetings. The large audience was made up of interprofessionals (and a few parents) from across the country with various practice and research experience in the pediatric palliative care field.

Special Interest Articles:

- CHCPA Conference Highlights
- Updated Vision Statement
- Interesting Links

Many of us can remember as recently as about 5 years ago when there were only a handful of professionals in the room who were working with children! The opportunity to engage with other like minded folks was quite inspiring, launching new ideas, energy and project/research ideas.


Several members of TRAC-PG presented oral presentations, posters, workshops and panel sessions (please see our second page for more details). Several of these and other presentations from the conference can be downloaded at:

<http://www.conference.chpca.net/>. An extra special thanks goes to Maria and Chris for their involvement in the conference planning and for their gentle prodding in moving the pediatric agenda forward.

Mark it in your books that the next CHPCA Conference, "Crossing the Bridge to Knowledge and Sharing", will be held from October 26-29, 2008 in Charlottetown, Prince Edward Island. Given the number and growth of international palliative care conferences, the challenge will be in finding the "right" niche for the pediatric stream.

Laura

Check out our website:
www.sickkids.ca/palliativecare
forhcp



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*Recently Published:
Pediatric Patients
Receiving Palliative
Care in Canada
Kimberley Widger,
Dawn Davies, Danielle
Drouin, Laura Beaune,
Maria Rugg et al.
Arch. Pediatric
Adolesc Med/Vol. 161.
June 2007:597-602*

CHPCA Conference Presentations by TRAC-PG Members:

Barrera, M. *Parental self-identity trajectories after the death of a child to cancer*

Beaune, L., Barrera, M., Steele, R., Newman, C., & Rugg, M. *Developing a children's palliative care research team: A careful journey.*

Bouffet E., Brownstone D., Chau T., Eaton Russell C., Van Halderen C. *Beyond Words: Family communication when a dying child can no longer speak.*

Eaton Russell C., Warnick A. *Children Living with Dying: Through their eyes, in their words.*

Ives-Baine, L. *Can Knowledge about Health Care Professionals' Needs and Concerns in End-of-Life Care in the Neonatal Intensive Care Unit Lead to Better Care of Grieving Families? Development of a Guidebook for End-of-Life Care Based on Research*

Rugg, M. *Understanding Advance Care Planning Among Health Care Professionals Caring for Children with Life Threatening Illness*

Cadell, S., Davies, B., Siden, H., Steele, R., & Straatman, L. *Team building and challenges: Best practices.*

Cadell, S., Davies, B., Siden, H., Steele, R., Straatman, L., Hemsworth, D., & Liben, S. *Caregiving parents of children with life-limiting illnesses: Beyond stress and coping to growth.*

Bosma, H., Fletcher Johnston, M., Cadell, S., Davies, B., Siden, H., Steele, R., Straatman, L., & Fleming, C. *Research priorities in pediatric palliative care: A Delphi study.*

Ho, G., Jacques, L., Cadell, S., Davies, B., Siden, H., Steele, R., & Straatman, L. *Multicentre research in pediatric palliative care: Navigating through multiple research ethics boards.*

Updated Vision for TRAC-PG:

In order to meaningfully capture the breadth and depth of TRAC-PG's collective work and goals, the group discussed and revised our Vision Statement during our strategic planning process this Fall (2007). Through thoughtful and stimulating discussion, the 'Vision' emerged as:

To generate and disseminate knowledge about infants, children and adolescents with a potentially life limiting illness and their families in order to optimize quality of palliative, end of life and bereavement care.

Interesting Links:

Canadian Virtual Hospice: www.cvh.ca

International Palliative Care Children's Network: www.icpcn.org.uk



