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Volume 3: Summer Edition

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



A PROJECT FUNDED BY : CHILD HEALTH EVALUATIVE SCIENCES (RI/SICKKIDS), B.R.A.I.N CHILD, THE DIVISION OF HAEMATOLOGY & ONCOLOGY (SICKKIDS) AND CHILD HEALTH SYSTEMS (SICKKIDS)

# Welcome to our Summer 2008 Newsletter (Third Edition)

### First Meeting with the new Advisory Board

TRAC-PG is pleased to announce that the new Advisory Board has come together. This group will meet twice a year to provide guidance and expertise in research priorities, as well as to endorse and support the activities of TRAC-PG and in influencing the growth of pediatric palliative care and research. On June 25<sup>th</sup> the first meeting was held. The executive members of the board are **Dr. Maru Barrera**, PhD, Psychologist, Haematology/Oncology, **Laura Beaune**, MSW, Palliative and Bereavement Care Service Research Coordinator, and **Dr. Christine Newman**, MD, Palliative Care Physician, Palliative and Bereavement Care Service, SickKids.

The other members of the board are **Cathy Bankert**, Parent, **Malcolm Berry**, Parent, and Development Officer, GEP, SickKids Foundation, **Mitch Blum**, Parent, **Dr. Mark Greenberg**, Parent, MD, Senior Physician Haematology/Oncology, SickKids, Medical Director, Pediatric Oncology Group of Ontario (POGO) and POGO Chair in Childhood Cancer Control, University of Toronto, **Julie Lachance**, Senior policy analyst, Palliative and End of Life Care, Health Canada, **Lorelei Lingard**, Educational Researcher, Associate Professor, SickKids Learning Institute, **Alison Quigley**, Executive Director, Child Health Network, **Karen Spalding**, RN, PhD, Program Director, Master of Nursing, Ryerson University, VP Child and Youth Home Care Network, and **Jodi Hamelin**, MSW student from the University of Toronto and new research assistant for the Palliative and Bereavement Care Services at Sick Kids.

### Special Interest Articles:

- First Meeting with new Advisory Board
- Innovative Fund in Children's Palliative Care Research
- Upcoming Conferences

### Do you have a research project that needs funding???

#### Introducing the Innovative Fund in Children's Palliative Care Research

The Innovation Fund in Children's Palliative Care Research, is a fund made up of several family funds, including the Sasha Bella Fund for Family Centred Care, in support of pediatric palliative care research. The Fund has agreed to make an annual gift of up to \$10,000.00 to TRAC-PG each year for the next 5 years to support new innovations in children's palliative care research. Funds may be used to support: grant writing, program/evaluation development, LOI's, educational activities related to research or for pilot or seed grant research projects.

Any health care professional/volunteer or team of health care professionals or volunteers (hospital and/or community), including members of TRAC-PG, will be eligible to submit a proposal and all potentially life limiting illnesses with respect to children will be considered.

**Deadline for submissions is: September 8<sup>th</sup>, 2008**

Contact Laura Beaune for more information at 416-813-7654 ext. 3372

### Publications by TRAC-PG Members thus far in 2008

- 1) **Rugg, M.** Advance care planning in pediatric palliative care: Do we really know what they are asking? Hot Spot. Volume 10, Issue 2 May 2008
- 2) **Steele, R.**, Bosma, H., Fletcher, M., Cadell, S., Davies, B., Siden, H & Straatman, L. (in press 2008) Research Priorities in Pediatric Palliative Care: A Delphi Study. *Journal of Palliative Care*.
- 3) Straatman, L., Cadell, S., Davies, B., Siden, H., & **Steele, R.** (in press 2008). Update on pediatric palliative care research: Development of a New Emerging Team. *Paediatrics & Child Health*.
- 4) **Steele, R.**, Derman, S., Cadell, S., Davies, B; Siden, H., & Straatman, L. (in press 2008). Exploring families' transition into a pediatric hospice: Part I. *International Journal of Palliative Nursing*.
- 5) **Steele, R.**, Derman, S., Cadell, S., Davies, B; Siden, H., & Straatman, L. (in press 2008). Exploring families' transition into a pediatric hospice: Part II. *International Journal of Palliative Nursing*.
- 6) **Widger, K.**, Picot, K., (2008) Parents' perceptions of the quality of pediatric and perinatal end-of-life care. *Pediatric Nursing*, 34 (1) 53-58
- 7) **Barrera, M.**, O'Connor, Mammon, D'Agostino, et al. (2008) Early parental adjustment and bereavement after childhood cancer death. *Death Studies* (in press).

### Journal Club

The journal club is on holidays for the summer months, but will be reconvening on Monday March 16<sup>th</sup>, 2009 from 10:30 to 12:00 pm. This club meets every few months to discuss current journal articles and research initiatives that are relevant to pediatric palliative care. Contact Laura Beaune for information on this club at 416-813-7654 ext. 3372

### Upcoming Conferences

#### The 17<sup>th</sup> International Congress on Palliative Care

Will be held at the Palais des Congres in Montreal Quebec on **September 23-26, 2008**  
For more information visit: <http://www.pal2008.com>

#### Canadian Hospice Palliative Care (CHPCA) Conference

Will be held at the Delta Prince Edward on **October 26-29, 2008** in Charlottetown, Prince Edward Island. For more information visit: <http://conference.chpca.net>

#### The 14<sup>th</sup> Annual Science and Art of Pain and Symptom Management Conference

Will be held at the University of Toronto, St. George Campus on **November 22, 2008**  
The detailed program brochure and registration information will be available in Fall 2008  
Check out [www.cme.utoronto.ca](http://www.cme.utoronto.ca) after September 15<sup>th</sup> for more information

### Coming in May 2009....

Research Symposium during Palliative Care Week at Sick  
Stay tuned for further information on this event

For more info  
contact Laura at  
416-813-7654  
ext. 3372

### Coming Soon.....

TRAC-PG will  
soon have its own  
website!

Check out our  
launch page at  
[www.tracpg.ca](http://www.tracpg.ca)

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