



Welcome to our Spring 2009 Newsletter

What's New with TRAC-PG:

Innovation Grant:

The **Innovation Fund** in Children's Palliative Care Research, is a fund gifted by families and individuals, including the Sasha Bella Fund for Family Centred Care, in support of pediatric palliative care research. The Fund has contributed a gift of up to \$10,000.00 to TRAC-PG (The Team for Research in Adolescent and Childhood Palliation and Grief at SickKids) 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, clinical projects with an evaluation component or for pilot or seed grant research projects.

Call for abstracts coming up for submission in October 2009!
Application forms can be found on our website at www.tracpg.ca.

First recipients of the Innovation Fund in 2008:

Susan Cadell PhD, MSW, Rose Steele RN, PhD, and Anita DeLongis PhD. "Better Understanding How Couples Cope with a Child's Life-Threatening Illness". Manulife Centre for Healthy Living, Lyle S. Hallman Faculty of Social Work. Wilfrid Laurier University. \$1800.00

Kimberley Widger RN PhD(c), CHPCN(c) Ann Tourangeau, RN, PhD, Rose Steele RN, PhD, David Streiner, PhD. "Development and testing of an instrument to measure parents' perspectives of the quality of children's end-of-life care. Lawrence S. Bloomberg Faculty of Nursing. University of Toronto. \$4,874.00

New Members:

Susan Cadell PhD, MSW, Wilfred Laurier University

Christopher Obwanga, Research Coordinator, Temmy Latner Centre

Dr. Nadine Cross, PhD, Nursing, York University

Dr. Gail Lindsay, PhD, Nursing, University of Ontario Institute of Technology

Welcome to the TRAC-PG Website! - www.tracpg.ca

Seeing as TRAC-PG is a fast growing team, we felt the next step was to make research information and resources regarding palliative and bereavement care readily available on the net. And thus, our website was born!

The website is filled with details for children and families, health care providers, volunteers and anyone else interested in finding out more about pediatric palliative care.

We are proud to provide lots of information about end-of-life care, research and community resources, research opportunities, policy and advocacy initiatives, and offer a place where families and health care providers can connect with one another.

Special Interest Articles:

TRAC-PG New Website

Research Symposium

The Family Corner

Congratulations:

Jodi Hamelin—
graduated
MSW!

Congratulations:

Kim Widger—
who is a CIHR
Fellowship
Winner!



Congratulations:

Maria Rugg-

Received a 6 month
secondment at the
Coroners office!

Congratulations:

Lori Ives-Baine-

Graduated Reg. N.,
M.N., C.P. Bioethics!

Research Symposium— SickKids Hospital – October 14th, 2009:

Please join us and learn about some of the ethics, benefits and challenges in pediatric palliative care research. There will be opportunities for networking, an interesting Café Scientifica, specialized keynote speakers, and a panel discussion with parents and researchers.

The Family Corner:

“I think siblings often suffer more than the ill child. Siblings need to be given emotional support and verbal feedback to help them maintain some sense of normalcy in their lives (p. 199)” Murray, J. (1999a). Methodological triangulation in a study of social support for siblings of children with cancer. *Journal of Pediatric Oncology Nursing* 7(6), 194-200.

“My name is Jodi Hamelin and I am 25 years old. In August 1996 I was 12 and my brother Jeff was 15 when he was suddenly diagnosed with two malignant brain tumors. This is my story.

I remember very specifically where I was standing, in the atrium at Sick Kids when my mother told me that my brother had cancer. Life as I knew it changed at that moment. Although my brother survived, is healthy and now 27 years old, my family’s experience with cancer was something that had a huge impact on all of our lives. It took me a long time to heal from my own experience but I have learned that being the sibling of a child who had cancer has shaped who I am today. Jeff was lucky. His tumors were discovered relatively early, and after only four months he had his last cancer treatment on Christmas Eve and his tumors were gone.

The biggest disruption to my family’s life was the fact that Jeff was treated in Toronto, two hours from our home. I was not as involved with my brother’s treatment as I wanted to be. I wanted to be at the hospital so I could see what was going on. But because I was “stuck” at home, I got involved in every extra-curricular activity that I could. I did anything outside of school to keep myself busy and out of my house. I tried to preoccupy every moment of my day so that I would not have to think about cancer.

I was old enough to know what cancer was. It was explained to me that Jeff’s chance of survival was 85%. My parents told me this but I thought they were lying. I thought they were saying this so that I would not worry. Instead, I constantly feared the worst. I was convinced that my brother was dying. I was also told that there was no chance of me developing the same tumors that Jeff did. Again I struggled believing this. I was almost certain that I would develop the same cancer. I especially felt this way a couple of years later when I turned 15, and was the same age that Jeff was when he was diagnosed.

Luckily for me, one of my mother’s friends recognized that I was struggling and she became my main support system during this period in my life. I truly believe that without her I would have struggled much more throughout this experience. If I could offer any advice to parents it would be to ask for help from family and friends. Although parents may not be able to support healthy children during a child’s cancer treatment, they do need support.”

Jodi can be contacted at jodi.hamelin@utoronto.ca. Jodi is a part-time research assistant with TRAC-PG and recently graduated with her MSW from UofT.



Congratulations:

Laura Beaune,
Jodi Hamelin &
David Nicholas –
Having a winning
poster at the 2009
OHA/HPC
Conference!

Volunteer to Join a Study:

Investigators: Kimberley Widger (PhD Candidate)
Dr. Ann Tourangeau (PhD Candidate Supervisor)

Are you the parent of a child who died at home after a life-limiting illness?

We are looking for parents to take part in a study about the quality of care provided to dying children and their families. We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed.

If your child (aged 19 years and under) died in a hospital at least one year ago, after an admission of at least 24 hours you can take part OR if your child died at home at least one year ago after a life-limiting illness you can take part. For this study you will be asked to attend a focus group with other parents held in the Toronto or Hamilton area to talk about your experiences and what you feel is important to providing the highest quality care. The focus groups will last about 2 hours. The focus groups will be held in English.

For more information, or if you are interested in taking part in this study please contact Kimberley Widger at 416-978-2859 or kim.widger@utoronto.ca. Please leave your name and phone number so we can contact you to talk more about the study.

New Publications:

Rugg, M. (May 2008) Advance care planning in pediatric palliative care: Do we really know what they are asking? Hot Spot 10(2)

Barrera, M., O'Connor, K., D'Agostino, N.M., Spencer, L., Nicholas, D., Jovcevska, V., Tallet, S., & Schneiderman, G. (2008 In Press) Early Parental Adjustment and Bereavement after Childhood Cancer Death Death Studies

Steele, R., Bosma, H., Fletcher Johnston, M., Cadell, S., Davies, B., Siden, H., Straatman, L. (2008) Research priorities in pediatric palliative care: A delphi study Journal of Palliative Care, 24, 229-287

Widger, K. & Picot, K. (2008) Parents' perceptions of the quality of pediatric and perinatal end-of-life care Pediatric Nursing, 34(1), 53-58

Rapaport, A. (May/June 2008) A place to die: The case for paediatric inpatient hospices Paediatric Child Health, 13(5), 369-370

Straatman, L., Cadell, S., Davies, B., Siden, H. & Steele, R. (2008 In Press) Update on pediatric palliative care research: Development of a new emerging team Paediatrics and Child Health