



December 2009

Volume 5: Fall Edition

Welcome to our Fall 2009 Newsletter

What's New with TRAC-PG:

Innovation Fund in Children's Palliative Care Research- 2009 Winners:

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*, the *SickKids Foundation* and the *Social Work Research Endowment Fund* at SickKids, in support of pediatric palliative care research. In 2009, the Fund has agreed to make a gift of up to \$22,000.00 to TRAC-PG to support new innovations in children's palliative care research.

This year's winners are:

Mary Ellen Macdonald, PhD, Stephen Liben, MD, Montreal Children's Hospital; Susan Cadell, PhD, Wilfrid Laurier University; Ms. Lorie Kloda, Life Sciences Librarian, McGill University *A systematic review of bereavement after the death of a child: A meta-synthesis of literature on family bereavement experiences and interventions.* \$4,459.00

Simone Stenekes RN, MN, CHPCN(c), Mike Harlos MD, CCFP, FCFP, Winnipeg Regional Health Authority (WRHA); Carla Ens PhD, Manitoba FASD Centre; Devon Brown RN, BN, Harvey Max Chochinov MD, PhD, FRSC, University of Manitoba; Susan Kuling, Royal University Hospital, Saskatoon Health Region *Perinatal Palliative Care: Measuring the Impact of Manitoba's Pediatric Symptom Management and Palliative Care Service (PPCS).* \$4,015.00

Dr. David Nicholas, PhD, University of Alberta; Laura Beaune, MSW, Res. Dip. SW, Dr. Maru Barrera, PhD, The Hospital for Sick Children; Jonathan Bloomberg, The Wire *Understanding the experiences and support needs of fathers of children with life-limiting illnesses.* \$5,000.00 plus \$2,000.00 from the SickKids Social Work Research Endowment Fund

Barbara Muskat, PhD, MSW, RSW, Samantha Anthony, MSW, RSW, Res.Dip.SW, Laura Beaune, MSW, Res Dip. SW, David Brownstone, MSW, RSW, Pam Hubley, RN, MSc, ACNP, Christine Newman, MD FRCP(C), Adam Rapoport, MD, FRCPC, MHSc, The Hospital for Sick Children *Experiences and perceptions of paediatric health professionals providing end of life and palliative care.* \$5,000.00 plus \$2,000.00 from the SickKids Social Work Research Endowment Fund

Thank you to our sponsors and to our applicants!

New Members:

This year TRAC-PG has continued to grow with the addition of new members:

Anna Cooper, RN, *Child and Family Services, CCAC Toronto*

Gurjit Sangha, RN, MN, *Clinical Nurse Specialist, Palliative & Bereavement Care Service, SickKids*

Heather Urquhart, RN, BScN, Med, APN, *Advanced Practice Nurse, NICU, SickKids*

Stephanie Lappan-Gracon, *Manager Child Health Services, SickKids*

Joan Turner, *Parent; M. Ed(c), University of Toronto*

Lia Juskey, RN, *Critical Care Unit, SickKids*

Kevin Weingarten, MD, *University of Toronto*



TRAC-PG Pediatric Palliative Care Research Symposium:

“Dispelling Myths: Benefits and Challenges in Research with Children and Families”

The first Innaugural Pediatric Palliative Care Research Symposium was on October 14, 2009, and was a GREAT success!

The day was filled with key note speakers, an exciting movie and panel discussion, Café Scientifica poster presentations, a workshop, and an evening social. The symposium was open to family members, researchers, clinicians, and volunteers.

Many thanks to our sponsors: The SickKids Foundation, Sasha Bella Fund & CDP!



For any information, go to our website at:

http://www.tracpg.ca/index.php/researchers/trac-pg_pediatric_palliative_care_research_symposium/

Stay tuned for information on next year's symposium!

CALL OUT for New Members for the Innovation Fund Grant Review Committee:

We are looking for individuals who are interested in sitting on the Grant Review Committee for The Innovation Fund in Children's Palliative Care Research. The group meets twice per year to evaluate and discuss submitted applications.

If you are interested, please contact Laura Beaune at (416) 813-7654, ext. 3372 or at laura.beaune@sickkids.ca

Awards and Congratulations:

Congratulations to TRAC-PG member, Dr. Lillian Sung, who is this year's recipient of the William E. Rawls Award in Cancer Control

Please join us in congratulating Jodi Hamelin!

Jodi, a previous member of the TRAC-PG team, has moved into a clinical social work job at McMaster Children's Hospital in the diabetes outpatient clinic.

TRAC-PG Website

Our website has continued to expand with tremendous success. Continue to look for upcoming events, workshops and conferences related to pediatric palliative care. You can also keep track of updated studies, publications and other work by our members. More recently added to the web are wonderful memorials from bereaved families, a growing photo gallery and information on how TRAC-PG is growing.

Don't forget to visit us www.tracpg.ca



The Family Corner:

First Camp Erin in Canada hosted by Max and Beatrice Wolfe Children's Centre and Dr. Jay Children's Grief Program

My strongest memory of the weekend is watching the nighttime lake alight with individual candles, floating out on their individual journeys over the water. This lake of flickering lights was mirrored in different ways - by both the multitude of stars blanketing the huge sky otop of our weekend grief camp, and also by the 55 children and 34 volunteers who stood together on the shoreline, each responsible for setting one of those candles afloat, each in memory of someone who had died in their life, each in their own individual journey of grief.

This first Camp Erin Toronto, held in Muskoka from September 11 - 13, was special. The first Camp Erin in Canada, this year's Camp Erin Toronto was made possible thanks to a start-up grant awarded to the Max and Beatrice Wolfe Children's Centre and the Dr. Jay Children's Grief Program from The Moyer Foundation in Seattle. Established by Major League All-Star pitcher Jamie Moyer and his wife, Karen, the Moyer Foundation supports 28 Camp Erins across the US, providing grief camps for thousands of bereaved children each year. It was also special because it was transformative for the kids from across the GTA and beyond who got to join with other children, youth and adult staff and volunteers to share in a weekend of grief camp and discover that they are not alone in having had a loved one die.

Together, we played games, made art and crafts, canoed, swam, did drama, and participated in a host of other campy experiences. As well, we engaged the group in numerous grief activities where the children could honour and remember their loved one who died, to express the many faces of their grief, and learn skills and tools to work with their grief in the months and years to come.

Feedback from one parent says it best: "When I asked Kevin [name changed] what he liked best about the experience, he said, "Everything". I know Camp Erin made an impression on Kevin, to see that there were other children with difficult times too. I think too that at his age now, he is processing his daddy's death from a different developmental stage and perspective. Even though it has now been 3 years since his daddy's death, Kevin is still trying to figure things out. He now has more consciousness and reasoning ability and the fact that he continues to have support and opportunities like Camp Erin is so important! Thank You. Thank You. Thank You."

Another 13-year old boy put it more succinctly: "It feels good to be able to cry."

We are grateful to be able to offer programs like this to families free of charge, to eliminate the financial barriers that prevent many families from being able to access this kind of support. For any information about this program contact Lysa Toye at (416) 568-4800, ext. 6148.

Story by: Lysa Toye, MSW, RSW, Dip EXAT
Counsellor
Max and Beatrice Wolfe Children's Centre
The Temmy Latner Centre for Palliative Care, Mount Sinai Hospital
Joseph and Wolf Lebovic Centre



New Studies by TRAC-PG Members:

“Stress and growth over time: Caregiving and bereaved parents of children with life-limiting illnesses”
Investigators and Staff: Susan Cadell, Betty Davies, David Hemsworth, Stephen Liben, Hal Siden, Rose Steele & Lynn Straatman

“Development and testing of an instrument to measure parents’ perspectives of the quality of children’s end-of-life care” Principal Investigator Ms. K. Widger, RN, PhD(c), CHPCN(C); co-investigators Dr. A. Tourangeau, RN, PhD; Dr. R. Steele, RN, PhD; and Dr. D. Streiner, PhD

“Better understanding how couples cope with a child’s life-threatening illness” Principal Investigator Dr. S. Cadell, MSW, PhD; co-investigators Dr. R. Steele, RN, PhD; and Dr. A. DeLongis, PhD

New Publications by TRAC-PG Members:

Widger, K., Davies, D., Drouin, D., Beaune, L., Daoust, L., Farran, P., Humbert, N., Nalewajek, F., Rattray, M., Rugg, M., Bishop, M. (2007). **Pediatric patients receiving palliative care in Canada: Results of a multicenter review.** Archives in Pediatric Adolescent Medicine, 161:597-602

Foster, T, Gilmer, MJ, Davies, B, Barrera, M, Fairclough, D, Vannatta, K, Gerhardt, C. (2009, In Press). **A qualitative study of continuing bonds: maintaining connections after the death of a child.** Death Studies.

Dupuis, LL., Milne-Wren, C., Cassidy, M., Barrera, M., Portwine, C., Johnston, DL., Silva, MP., Sibbald, C., Leaker, M., Routh, S., & Sung, L. (2009, In Press). **Symptom assessment in children receiving cancer therapy: the parents’ perspective.** Journal of Supportive Care in Cancer.

Foster, T, Gilmer, MJ, Davies, B, Barrera, M, Fairclough, D, Vannatta, K, Gerhardt, C. (2009, In Press). **Bereaved parents’ and siblings’ reports of legacies created by children with cancer.** Journal of Pediatric Oncology Nursing.

Rapoport, A. (2009). **Addressing ethical concerns regarding pediatric palliative care research.** Arch Pediatr Adolesc Med, 163(8), pp.688-691

Steele, R., Robinson, C., Hansen, L., & Widger, K. (in press). **Families and palliative/end-of-life care.**

Cadell, S., Ho, G., Jacques, L., Wilson, K., Davies, B., & Steele, R. (2009). **Considerations for ethics in multisite research in pediatric palliative care [Letter to the Editor].** Palliative Medicine, 23, 274-275

Widger, K., Steele, R. Davies, B., & Oberle, K. (2009). **Exploring the supportive care model as a framework for pediatric palliative care.** Journal of Hospice and Palliative Nursing, 11(4), 209-216

Antle, B.J., Montgomery, G., & Stapleford, C. (2009). **The many layers of social support: Capturing the voices of young people with Spina Bifida and their parents.** Health & Social Work, 34(2), 97-106

Barrera, M., O’Connor, K., D’Agostino, N.M., Spencer, L., Nicholas, D., Jovcevska, V., Tallet, S., & Schneiderman, G. (2009). **Early parental adjustment and bereavement after childhood cancer death.** Death Studies, 33, 1-24