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TRAC  PG

Team for Research in Adolescent and
Childhood Palliation and Grief

SPECIAL POINTS OF INTEREST:

- **What's New**
- **Fourth Annual Pediatric Palliative Care Research Symposium**
- **Staying Connected: A Handbook for Parents and Clinicians**
- **Cross-National Think Tank on Grief and Loss**
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- **Studies on the Go**
- **Winners of the Innovation Fund 2011**
- **Volunteer to Join a Study**

What's New?



Announcements, Achievements & Accomplishments

Congratulations to **Dr. Barbara Muskat**, PhD, on her appointment as the Clinical Director, Department of Social Work, SickKids. Barb is a member of TRAC-PG and holds several grants in the field of palliative care, and has a particular interest in compassion fatigue and resilience in health care providers care to dying children.

We are proud to have a new graduate amongst us! Congratulations to **Dr. Kim Widger**, our newest PhD (Nursing), Kim successfully completed her dissertation and thesis work at The University of Toronto with a focus on developing an instrument to evaluate parents' perspectives of hospital based quality of end-of-life care. She is also a top ranked recipient of a 3 year CIHR fellowship and will be working with Bonnie Stevens, Centre for Nursing, SickKids on the "Development of a knowledge translation strategy for enhancement of pediatric end-of-life pain management as well as other studies related to childhood pain.

Fourth Annual Pediatric Palliative Care Research Symposium

Hold The Date:

A Day about Grief & Loss

Wednesday October 24th, 2012 at SickKids

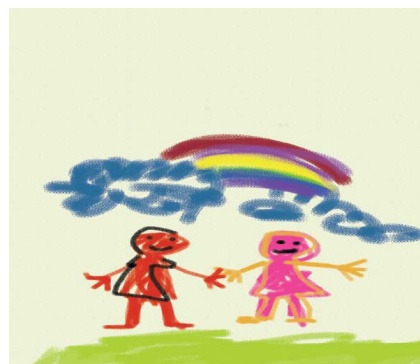
Symposium updates can be found at: www.tracpg.ca

Staying Connected: A Guide for Families When a Sick Child has Trouble Communicating

By: Ceilidh Eaton Russell BA, CLSt Dip, Eric Bouffet, MD, FRCP(C); David Brownstone, MSW, RSW; and Caelyn Kaise, M.H.Sc., SLP (C) Reg. CASLPO

Book Introduction:

Supporting a child or teenager who has a brain tumour is an incredibly important and difficult job. Trying to help them to understand and live with their changing abilities can be overwhelming, especially when caregivers naturally struggle with these changes themselves. It can also be a challenge because while physical abilities may change, cognitive abilities often stay intact. If a child or teenager has trouble communicating because of a brain tumour, the task of supporting them becomes even more complex.



In this handbook we have put together what we learned from talking with fourteen families about their experiences, as well as from our own experiences working with families. The parents we spoke with generously shared the creative strategies and tools that they developed, the most important conversations they had and the lessons they learned. When we began to talk with these parents, our goal was to develop a new communication tool. In the end, they taught us that although tools are helpful, direct communication was most valued and helpful. Families encouraged us to create this resource to share with other families like yours, so that you would have some ideas about where to start and what to try, and so that you would know that you are not alone.



Health care professionals and families may download this handbook by going to AboutKidsHealth (to be posted soon) or the TRAc-PG website: www.tracpg.ca. or the b.r.ai.n.child site at: <http://www.sickkids.ca/Brainchild/Resources-and-Links/>

Congratulations to Ceilidh and her team for creating such a meaningful and evidence based clinical tool for families and

Cross-National Think Tank on Grief and Loss:

New Conversations, New Partnerships, New Action, York University, Feb 10th, 2012

TRAC-PG is pleased to be a co-sponsor of this event at York University. To find out more, please contact Leeatg@gmail.com 647-891-8303

Recent TRAC-PG Publications

Kim Widger & Tourangeau A. (2011). *Room for improvement: Mothers' perspectives on children's end-of-life care*. *Journal of Palliative Care*, 27(3), 255.

Davies, B., **Kim Widger** **Rose Steele**, **Susan Cadell**, Siden, H., & Straatman, L. (2011). Research considerations. In J. Wolff, P. Hinds, & B. Sourkes (Eds.), *Textbook of interdisciplinary pediatric palliative care* (pp. 96-103). New York: Elsevier.

David Nicholas, Clare Patershuk, Donna Koller, Cindy Bruce-Barrett, Lucy Lach, Randi Zlotnik, Shaul, Anne Matlow, *Health Policy* 96 (2010) 134-142
Pandemic planning in pediatric care: A website policy review and national survey data

A Glimpse of TRAC-PG Studies On the Go

M. Barrera, Sung, L., Bartels, U., Janzen, L., Atenafu, A., Cataudella, D., Zelcer, S., Downie, A., Johnston, D., Brandon, S., Schulte, F., Strother, D., Briere, M., Chung, J., Hukin, J., McConnell, D. "A randomized wait-control trial to evaluate the efficacy of a social skills intervention for childhood survivors." Canadian Cancer Society Research Institute. (3 years), \$566,969.00

Dr. H. Siden, MD, MHSc; **Dr. S. Cadell**, MSW, PhD; Dr. B. Davies, RN, PhD, FAAN; Dr. D. Davies, MD; Dr. M-C Grégoire, MD, PhD; Dr. M. Harlos, MD; Dr. S. Liben, MD; Dr. M-E Macdonald, PhD; **Dr. A. Rapoport**, MD, FRCPC, MHSc; Dr. S. Spicer, MD; **Dr. R. Steele**, RN, PhD; Dr. L. Straatman, MD, FRCPC; and Dr. C. Vadeboncoeur, MD "PedPalAScNet: A network for accessible, sustainable, and collaborative research in pediatric palliative care". Canadian Institutes of Health Research Network, Catalyst Grant (\$375,328) 2011-2014

Innovation Fund in Children's Palliative Care Research 2011 Grant Recipients

This year 8 applications from across the country were made to the Innovation Fund, of which the following 3 submission were chosen. Thank you again to the Sasha Bella Fund for Family Centred Care and SickKids Foundation for their generous donations.

C. Meghan McMurtry, PhD, C. Psych, Department of Psychology, University of Guelph, Shannon Marshall, RMT, Jennifer Stinson, RN, PhD, CPNP. Chronic Pain Program, The Hospital for Sick Children, **Adam Rapoport**, MD, FRCPC, MHSc, Palliative and Bereavement Care Service, The Hospital for Sick Children, **Maria Rugg**, RN, BScN, MN, CHPC(C) Manager, Psychosocial Oncology & Supportive Care, Peel Regional Cancer Centre, Credit Valley Hospital, Mississauga “*Feasibility and initial effectiveness of massage therapy for pain and anxiety reduction and improved quality of life in palliative children with cancer*”
Amount Awarded: \$4,000.00

Simone Stenekes RN, MN, CHPCN (c) - Clinical Nurse Specialist, Pediatric Palliative Care Service - WRHA Palliative Care Program; Clinical Nurse Specialist – Canadian Virtual Hospice, Genevieve Thompson - RN, MN PhD - Faculty of Nursing, University of Manitoba, Research Associate - Manitoba Palliative Care Research Centre, CancerCare Manitoba, Mike Harlos MD, CCFP, FCFP Medical Director, WRHA Palliative Care Program & Pediatric Palliative Care Service; Professor and Section Head, Palliative Medicine, University of Manitoba; Physician Consultant – Canadian Virtual Hospice, Marie-Claude Proulx RN, MScN - Clinical Nurse Specialist, Pediatric Palliative Care - Montreal Children's Hospital, Jamie Penner RN, MN - Doctoral Student, School of Nursing, McGill University, Stephen Liben MD - Director, Pediatric Palliative Care Program - Montreal Children's Hospital, Grace MacConnell RN, MN - Clinical Nurse Specialist, Palliative Care Service - IWK Health Centre, Marie-Claude Gregoire MD, MSc, FRCPC - Physician, Palliative Care Service - IWK Health Centre, Assistant Professor, Pediatrics & Anesthesia, Dalhousie University, Halifax, NS “*Development of a Perinatal Palliative Care Survey*”
Amount Awarded: \$4,000.00

Laura Beaune, MSW, Res Dip SW, Research Coordinator, Palliative and Bereavement Care Service, SickKids, Dr. Lee Ford-Jones, MD, Social Pediatrics, Pediatric Medicine, SickKids, Lee Ann Chapman, Lawyer, Family Legal Health Program, SickKids, Stanley Ing, Clinical Research Project Coordinator, Child Health Evaluative Sciences, Research Institute, SickKids, Dr. Adam Rapoport, MD, FRCPC, MHSc, Medical Director, Palliative and Bereavement Care Service, SickKids, Randi Zlotnik Shaul J.D., LL.M., Ph.D., Bioethicist, Department of Bioethics, Child Health Evaluative Sciences, SickKids, Rachel Vanderlaan, PhD, MD (candidate), Medical Student, Social Pediatrics, SickKids “*The Prevalence of poverty among families of children with life-limiting illnesses: an exploratory 5 year review of children receiving care from the Palliative and Bereavement Care Service at SickKids*”
Amount Awarded: \$2,000.00

Volunteer to Join a Study

Have you experienced the death of
your child from a life-limiting illness?

Dr. Susan Cadell, Associate Professor, Wilfrid Laurier University, Faculty of Social Work and colleagues are currently conducting a study of bereaved parents who have cared for a child with a life-limiting illness. We are looking for parents/guardians who are willing to share the story of caring for their child, the story of their death and how that experience changes parents' lives. We recognize that sharing the life and death of your child is both sacred and difficult. The information provided will help caregivers, social workers and medical staff better understand and support families during the care and death of a child. We appreciate the courage and time taken to assist us in this study. For this study, you will be asked to complete a set of questionnaires at two separate times. The questionnaires will be sent to you by mail and will take 1 to 1.5 hours to complete. Participants will not be identified in the study. Questionnaires are available in either English or French. For more information, or if you are interested in participating in this study, please contact the Research Coordinator at 1-800-810-0721 or mchl@wlu.ca

Got Something to Tweet About?

The @SickKidsNews Twitter account has a strong following. If you have some exciting news to share, some interesting facts, a study needing to recruit volunteers or an event you would like to promote to the world, Twitter may be your answer. Send your requests for tweets to twitter.news@sickkids.ca

