

VOLUME 8:  
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TRAC  PG

Team for Research in Adolescent and  
Childhood Palliation and Grief

## What's New?

### The Research4kids Clinical Recruitment Database

This is a new database offered at SickKids that lets kids and families know about research studies going on at SickKids that require volunteers (with specific illnesses, diseases and/or conditions) as well as "healthy" volunteers. Check it out or register your study into the database (must be affiliated with SickKids) - <http://www.sickkids.ca/VisitingSickKids/whats-new/research4kids.html>.



Find out more about Social Work Competencies on Palliative Education and the 5 educational teaching modules go to the CHPCA website: <http://www.chpca.net/SCOPE>. Thanks to Dr. Susan Cadell for her exemplary leadership.

## Third Annual Pediatric Palliative Care Symposium

### REGISTRATION IS NOW OPEN

Register at : <http://www.cvent.com/events/paediatric-palliative-care-research-symposium-2011/event-summary-5341491edb294486a0e78dcc5bc99604.aspx>

Or at: [www.tracpg.ca](http://www.tracpg.ca)

Wednesday October 5th, 2011 at SickKids

The Circle of Care: Promoting Palliative Care at Diagnosis of a Life-Threatening Illness

Key Note Speaker:

Dr. Joanne Wolfe, MD, MPH

Director, Pediatric Advanced Care Team (PACT), Dana-Farber Cancer Institute, Assistant Professor of Pediatrics, Harvard Medical School, Boston

Join us for a full day of discussion and learning including: key note speaker Dr. Joanne Wolfe, an interdisciplinary panel debate, oral and poster research presentations by TRAC-PG

# The Family Corner

## Are you still sad?

Valerie McDonald

Someone asked me recently if I am still sad about the death of my daughter, Natalie. I was surprised by the question and even a little offended. Of course I'm still sad, but when I stopped to reflect, I realized that the sadness has changed in the nearly 12 years since she died.

Natalie was our middle child—the organizer, instigator and peace-maker between her two sisters. She died when she was 9 years old after being treated for leukemia for two and a half years. We had no idea how to carry on without her lively spirit in our family. When she died, we not only lost Natalie, we also abruptly lost the support of most of the health care providers who had cared for her and for us over many years. It was other parents who taught us most about how to cope with that shattering sorrow.

From our friends, we learned to celebrate our lively girl and include her in our lives. Every year, on her birthday, we invite her cousins and best friends to share her favourite meal of Fettuccine Alfredo and rhubarb cake. We can't give gifts to Natalie, so we give them to our guests instead. At Christmas, Santa still fills her stocking along with those of the rest of the family. On her "Death Day" (inspired by Nearly Headless Nick, Natalie's favourite Harry Potter ghost), we have a tradition of talking about how we can each do something to make our family better without Natalie.

During the first few years, each of these occasions was an unbearably sad reminder of her death. But gradually, we began to look forward to these remembering-Natalie-traditions. But the first time her best friend couldn't attend a birthday party, I was devastated. It felt as though some part of Natalie had died all over again.

Then another wise friend reminded me that a 16 year old would likely not have had a family birthday party and might even have outgrown Fettuccine Alfredo. I realized that our remembering-Natalie-traditions could also grow and change, just as she would have done.

On the first Death Day that our family could not be together, we decided that each of us would draw a picture in honour of Natalie, who was a talented and prolific artist. The forced change in tradition encouraged us to explore her passion ourselves and to try something that she loved. Death Day was once the saddest day of the year. But now it is a day of art and creativity.

This past March, we celebrated her would-have-been twenty-first birthday. After living for nearly 12 years without her, yes, I am still sad. But after nearly 12 years, there is space to remember and celebrate the gifts she gave us that continue to enrich our lives.

## Volunteer to Join A Study

### **Stress and Growth Over Time: Caregiving and Bereaved Parents of Children With Life-Limiting Illnesses**

Currently recruiting eligible bereaved families to participate in a study led by Dr. Susan Cadell.

Little is known about positive outcomes of caregiving and bereavement, particularly for parents who cared for seriously ill children. The purpose of this study is to explore the factors that allow parents to survive and even grow in the face of the stress of caregiving and bereavement. Mothers, fathers, and other caregivers (e.g., grandparents, guardians) who have lost a child under the age of 18 to a life-limiting illness are invited to participate.

If you are interested or would like more information please leave a mes-

sage toll-free at 1-800-810-0721 or contact Susan Cadell at [scadell@wlu.ca](mailto:scadell@wlu.ca)

### **Understanding the Experiences and Support Needs of fathers of Children with Life-limiting illnesses**

This study is looking for fathers of children with a life-limiting illness as well as bereaved fathers (from the GTA, Ontario area and the Edmonton areas). This study searches to understand the experiences and support needs of fathers of a child with a life-limiting illness or fathers who are grieving the death of their child.

If you are a father who would be interested in joining a focus group with other fathers please contact

Laura Beaune at (416) 813-7654 ext.3372 or at [laura.beaune@sickkids.ca](mailto:laura.beaune@sickkids.ca)

### **Psychological Functioning and Bereavement Care Needs of Bereaved Chinese Immigrant Families in Canada**

Currently recruiting eligible families to participate in a study supervised by Drs. David Cox and Betty Davies, and supported by Dr. Hal Siden.

The purpose of this study is to learn about the experiences of Chinese families whose family member (i.e., spouse, parent, young or adult child, and/or other relative) has died. For this study, the researchers are looking for participants who are: Chinese immigrants born in Hong Kong, Taiwan, or Mainland China; OR are Canadian-Chinese and have parents who were born in one of those 3 regions. This study will involve talking to a researcher who speaks English, Mandarin, and Cantonese.

If you are interested or would like more information please contact Greenly Ho at (604) 875-2000, extension 5340.

## Recent TRAC-PG Publications

Davies, B., Widger, K., Steele, R., Cadell, S., 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

Foster, T., Gilmer, M., Davies, B., Dietrich, M., Barrera, M., Fairclough, D., Vannatta, K., & Gerhardt, C. (2011). Comparison of continuing bonds reported by parents and siblings after a child's death from cancer. *Death Studies*. 35:5, 420-440

Granek, L., Grief as Pathology: The Evolution of Grief Theory in Psychology From Freud to the Present (2010) *History of Psychology*, Vol. 13. No 1, 46-73

## A Glimpse of TRAC-PG Studies On the Go

Palliative medicine physician's knowledge and comfort caring for pediatric patients. Non Funded. September 2010—Ongoing. Principal Investigator: Dr. A. Rapoport, MD, FRCPC, MHSc.; co-investigators Ms. F. Srianni, Dr. A Husain, MD, FRCPC & Dr. L. Librach, MD, FRCPC

Development and testing of an instrument to measure parents' perspectives of the quality of children's end-of-life care. 2008-2011. Innovation Fund in Children's Palliative Care Research. \$4874.00 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

The purpose of the proposed study is to develop and test an instrument to measure the quality of end-of-life care provided to families before, at the time of, and following the death of a child, from the perspective of parents.

# Grief in the 21st Century

## Who's Afraid of Big Bad Grief? By: Dr. Leat Granek

No one, as it turns out.

While the contemporary discourse around grief and loss is that people want to avoid it-- talking, feeling, thinking about it – it seems from a recent series of projects on the topic, that this is simply untrue. People very much want to talk about their losses.

At a time where the debate continues to rage about how to manage (and medicalize) grief, alternative voices of dissent are ringing loudly in the virtual world.

Meghan O'Rourke, a writer, poet and friend and I recently proposed a series of articles on grief and loss for the online magazine, *Slate*. For our first piece, we designed a fairly simple survey to capture what people's experiences of grief were like from their own subjective points of view. (See: <http://www.slate.com/id/2289332/>).

Within one week we had 8000 responses! Not only did thousands of people take the time to fill out the extensive questionnaire, they took the opportunity to 'expand on their thoughts' in the optional text boxes providing us with rich, informative, honest heart wrenching stories about their losses.

In the second article we wrote up the results of the survey. (See: <http://www.slate.com/id/2292126/>). This time we had a series of comments on the site and a deluge of personal emails from people responding to our piece and making comments about what they had read, felt, and experienced.

One blogger, who captured the sentiment of many of our readers, wrote:

"My daughter died 17 months ago. Reading this article definitely spoke to me because I do feel isolated by grief, I feel terrible bringing it up to people who don't know because it stops people in their tracks and often makes them uncomfortable. So, my only resort is therapy where I can cry and share my sadness. But even the therapist seems to have a hard time with my sadness in what seems to me like a short time. "

Ironically, while many people resonated with this blogger in that they felt isolated in their grief, there was also clearly a deep desire to open the dialogue about grief and move it into the center, rather than the margins, of the conversation.

Eight thousand people filled out the survey. Seventy five thousand people read the article (or at least went to the article site): both are evidence of a burgeoning cultural shift towards talking more openly about grief.

Stay tuned for the next set of articles where we report on what people found helpful and harmful in coping with their losses.