

VOLUME 7:  
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Team for Research in Adolescent and  
Childhood Palliation and Grief

**SPECIAL  
POINTS OF IN-  
TEREST:**

- **What's New**
- **3rd Annual Palliative Care Research Symposium**
- **The Family Corner**
- **Call Out/Study Recruitment**
- **Studies & Publications**
- **The Innovation Grant**

## What's New With TRAC-PG

TRAC-PG has had a busy year! We have new investigators and co-investigators from across the province and our membership has grown exponentially.

Welcome to:

Dr. Barbara Muskat, PhD, SickKids

Ann Marie Guest, RN, CCAC,

Toronto

Leeat Granek, Psychology, McMaster

Children's Hospital, Pediatrics

Lisa Pearlman, NP, London Health Sciences

Congratulations to Dr. Adam Rapoport who has come on board as a Co-Director of TRAC-PG. Thanks to Dr. Christine Newman for her contributions over the past 2 years.

TRAC-PG Member Highlights:

- Initiated 9 new studies (over \$436,000.00 in grants)
- Produced 16 publications
- Conducted 10 presentations

A full list of our publications and presentations is available on request or check our website.

## Third Annual Pediatric Palliative Care Research Symposium

Hold the Date!

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

members and much more.

# The Family Corner

## Honouring the voices of our children: how bereaved parents contribute to pediatric health care

**Contributors:** Valerie McDonald, Joanie Turner, Jonathan Blumberg, Shari Morash, Malcolm Berry, Michelle Murray, Winnie Seto, Denise Bebenek, Elizabeth Peeters.



### Honouring children's voices

Although bereaved parents are no longer involved as partners in the care of their own children, many seek to make meaning out of their loss by helping others. Research shows that bereaved parents who help others are better able to find meaning in their child's death; this experience contributes to effective coping (Videka-Sherman: 1982; Schwab: 1990). Parents also report that talking with other parents and maintaining contact with staff at the treating hospital helped healing (D'Agostino: 2008.) This presentation is a preliminary inventory of the ways in which bereaved parents continue to contribute to pediatric health care services.

### Findings

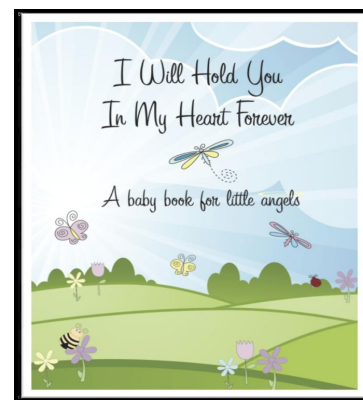
Activities fall within the following areas:

- Advocacy
- Direct Service to other families
- Research
- Policy
- Program development
- Fundraising
- Education



### Methodology

This preliminary inventory presents the activities of a small sample of parents (20) whose children were treated at Sick Kids and who continue to contribute to paediatric health care in some way.



*This poster and oral presentation were presented at the Second Annual Pediatric Palliative Care Symposium at SickKids on September 29th, 2010. The poster may be viewed in its entirety at [http://www.tracpg.ca/index.php/researchers/trac-pg\\_pediatric\\_palliative\\_care\\_research\\_symposium/](http://www.tracpg.ca/index.php/researchers/trac-pg_pediatric_palliative_care_research_symposium/)*

## Volunteer to Join A Study

### “Stress and growth over time: Caregiving and bereaved parents of children with life-limiting illnesses”

This study is recruiting bereaved parents/guardians who would like to participate in a study looking at the experience of caring for a child with a life-limiting illness and how it changes parents' lives.

Contact: Kathy Wilson, Project Coordinator, (519)884-1970 ext.5261 or e-mail

[kwilson@wlu.ca](mailto:kwilson@wlu.ca)

### “Understanding the experiences and support needs of fathers of children with life-limiting illnesses”

This study is looking for fathers of children who are at end-of-life, as well as bereaved fathers (from the GTA, Ontario area). 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.

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

### “Charting the Territory: Determining and documenting trajectories for families where a child has a life-threatening condition”

This study would like to recruit children (and their families) who are both newly diagnosed or those with established conditions of any duration. Children and families will be recruited on an ongoing basis.

Contact: Gail Andrews, Project Coordinator

[gandrews@cw.bc.ca](mailto:gandrews@cw.bc.ca)

For more information on any of these studies, visit:  
[http://www.tracpg.ca/index.php/children/volunteer\\_to\\_join\\_a\\_study/](http://www.tracpg.ca/index.php/children/volunteer_to_join_a_study/)

## Recent TRAC-PG Publications

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

Bosma, H., Johnston, M., **Cadell, S.**, Wainwright, W., Abernathy, N., Feron, A., Kelley, M., & Nelson, f. (2010) Creating social work competencies for practice in hospice palliative care. *Palliative Medicine*, 24(1) 79-87

Davies, B., Contro, N., Larson, J., & **Widger, K.** (2010). Culturally-sensitive information-sharing in pediatric palliative care. *Pediatrics*, 125(4) e859-e865

Davies, B., & **Steele, R.** (2010) Supporting families in palliative care. In B. R. Ferrell & N. Coyle (Eds). *Oxford textbook of palliative nursing* (2nd ed. Pp. 613-627). Oxford, UK: *Oxford University Press*

Thomposin, A, L., Miller, K.S., **Barreram, M.**, Compas, B.E., Davies, B., Fairclough, D.L., Foster, T.L, Gilmer, M., Hogan, N., Vannatta, K, & Gerhardt, C.C (under review). A qualitative study of advice from bereaved parents and siblings. *Journal of Social Work*

## TRAC-PG Studies On the Go

“Feasibility pilot test study of group therapy for bereaved siblings”

\$14,999.00 Pediatric Oncology Group of Ontario,  
Barrera, M, Schulte, F, Hancock, E, Atenafu and Sung, E.

“Experiences and perceptions of paediatric health care professionals providing end of life and palliative care”

\$7,000.00 Innovation Fund in Children's Palliative Care Research and the SickKids Social Work Research Endowment Fund  
Muskat, B, Beaune, L, Brownstone, D, Hubley, P, Newman, C, & Rapoport, A.

“Perinatal palliative care: Measuring the impact of Manitoba's Pediatric Symptom Management and Palliative Care Service (PPCS)”

\$4,015.00 Innovation fund in Children's Palliative Care Research  
Stenekes, S, Harlos, M, Ens, C, Brown, D, Chochinov, H, & Kuling, S.

## Innovation Fund in Children's Palliative Care Research 2010 Grant Recipient



The Innovation Fund in Children's Palliative Care Research has now funded innovative palliative care research studies from all across Canada over the past 3 years. The fund is generously supported by donations from the Sasha Bella Fund in Family Centred Care and the SickKids Foundation. To date the fund has granted \$28,464.00!

Congratulations to the 2010 Grant recipients:

*"Siblings Perspectives: Toward a Better Understanding of their Involvement with a Dying Child"*

Grant Amount: \$9,860.00

Ceilidh Eaton Russell, Max & Beatrice Wolfe Children's Centre, Maru Barrera, SickKids, Laura Beaune, SickKids, Susan Cadell, Lyle s. Hallman Faculty of Social Work, Wilfred Laurier University, Adam Rapoport, Temmy Latner Centre for Palliative Care, Maria Rugg, SickKids, Rose Steele, Faculty of Health, York University, Kimberley Widger, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto.

The study will explore and describe the ways that healthy children engage with a dying sibling, how these compare to the ways that siblings want to engage with a dying brother or sister, and how these activities may support or be linked to the grief and bereavement experience of the surviving sibling including what role they may have in the presence of continued bonds.

## Congratulatory News

Dr. Adam Rapoport, Dr. Christine Newman, Maria Rugg and Rose Steele for their award winning poster at the 18th International Congress on Palliative Care, October 2010, Montreal, Canada  
Entitled: *"Parental perceptions of forgoing artificial delivery of nutrition and hydration during end of life care for their children"*



Dr. Christine Newman for receiving the 2010 Norman Saunders Humanitarian Award, SickKids



Dr. Maru Barrera for her Companionship Award as recognized by the Pediatric Oncology Group of Ontario.