

SPECIAL
POINTS OF
INTEREST:

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- Studies



Team for Research in Adolescent and
Childhood Palliation and Grief

What's New With TRAC-PG

TRAC-PG Parent Research Initiative

As a result of the high level of interest from those who attended the first TRAC-PG Paediatric Palliative Care Research Symposium in September 2009, the TRAC-PG team and a group of parents brought together their new and innovative research ideas.

Since there was so much positive feedback and excitement from the parents to get involved in research related to paediatric palliative and bereavement care, the next logical step was

to develop a process through which bereaved parents and parents caring for a child with a life-limiting illness could work collaboratively with the TRAC-PG team to conduct meaningful research. And thus, the Parent Research Initiative was created.

More information about the Parent Research Initiative can be found on our website at www.tracpg.ca

Some of the parent suggestions for research and clinical ideas included understanding more about;

- The “continuing relationship” with a deceased child;
- Palliative care in the ICUs;
- The “right time” to introduce families to palliative care
- The need/benefits of a hospital wide memorial
- Parent and child suggestions for improved family centered care initiatives

Second Annual Paediatric Palliative Care Research Symposium

Following the success of the Inaugural Paediatric Palliative Care Research Symposium in 2009, The Palliative and Bereavement Care Service at SickKids and TRAC-PG are pleased to announce the date for the second annual Paediatric Palliative Care Research Symposium at SickKids. The date has been

set for **Wednesday Sept 29, 2010.**

The one day **free** event will highlight Grand Rounds keynote speaker, **Myra Bluebond-Langner, PhD, Distinguished Professor of Anthropology, Rutgers University, Camden, NJ.** Oral and poster presentations, workshops, an

interesting panel discussion and an evening public town hall event. The focus will be on topics related to listening to the voices of dying children, innovative research methodologies, and creative knowledge translation strategies.. For updates on information about the Symposium, visit our website at www.tracpg.ca

TRAC-PG Website

We are constantly working on updating our website with new resources about paediatric palliative care, new research and literature, upcoming events and information about the many heroic families we come in to contact with.

Sasha Bella Stein-Blumberg



Matthew and Kerrin Bankert



Cristina Lezeu and parents



You can visit our Photo Gallery for more beautiful pictures that parents have sent us in memory of their child.

www.tracpg.ca

Any families or healthcare professionals who have special photographs that they would like published on this website can contact:

Laura Beaune at (416)

813-7654 ext. 3372, or

laura.beaune@sickkids.ca

The Family Corner

Josiah's Journey

Josiah "Jo-Jo" Scott Morash was born on July 28th, 2009 at St. Joseph's Health Care London, Ontario. Early in the pregnancy, Josiah was diagnosed with a rare genetic disorder known as Trisomy 13 or Patau's syndrome. As a result of this diagnosis Josiah was given only a 3% chance of surviving to term. Beating incredible odds, Josiah survived and came close to full term on his birthday. He became a "Miracle Baby". Due to complications of Trisomy 13, which included semi-lobar holoprosencephaly and a congenital heart defect, Josiah also died in the arms of his Mother and Father on his birth day.

In memory of Josiah's legacy his family has founded "Josiah's Journey" in support of the Neonatal Intensive Care Unit at St. Joseph's Health Care, London. The inaugural Memorial Walk in memory of Josiah will be held Sunday July 25th at Springbank Gardens in London, Ontario. For more information or to register or donate online visit

www.josiahsjourney.ca.



Josiah's big sister Sarah holding a blue teddy bear which is programmed with her brother's heart beat.



Baby Josiah

50 bright coloured balloons were released at Josiah's funeral. Each balloon carrying a hand-written message from his family.



"Our family received the very best of care at both St. Joseph's Health Care in London and Sick Kids Hospital in Toronto. Throughout our pregnancy we were continually surrounded by caring and compassionate doctor's and health care professionals who understood the depth of our love and commitment to our son Josiah. We felt truly blessed."

- Josiah's mother, Shari comments on the care Josiah received at St. Joseph's and SickKids

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

“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 the end-of-life, as well as bereaved fathers (from the GTA or Edmonton). This study seeks 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

“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

For more information on any of these studies, visit: http://www.tracpg.ca/index.php/children/volunteer_to_join_a_study/

Recent TRAC-PG Publications

Foster, T, Gilmer, MJ, Davies, B, Barrera, M, Fairclough, D, Vannatta, K, Gerhardt, C. (2009) **Bereaved parents' and siblings' reports of legacies created by children with cancer.** Journal of Pediatric Oncology Nursing, Vol. 26:6, 369-376

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

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

TRAC-PG Studies On the Go

A multi-dimensional strategy for knowledge translation in pediatric palliative care research

Principal applicant Dr. H. Siden, MD, MHSc; co-applicants Dr. S. Cadell, MSW, PhD; Dr. B. Davies, RN, PhD, FAAN; Dr. R. Steele, RN, PhD; and Dr. L. Straatman, MD, FRCPC

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

Charting the territory: Determining and documenting trajectories for families where a child has a life-threatening condition

Co-Principal Investigators Dr. H. Siden, Dr. R. Steele & Dr. A. Rapoport; co-applicants Dr. R. Brant, Dr. S. Cadell, Dr. B. Davies, Dr. L. Straatman, & G. Andrews

Important News



Josiah's
JOURNEY

1st Memorial Walk
In support of the Neonatal Intensive Care Unit at St. Joseph's Hospital

Walk, jog or stroll with us!
bbq lunch • prizes • kids entertainment

Sunday, July 25th
10 am - 1 pm
Springbank Gardens, London

Register online at www.josiahsjourney.ca



COME TO CAMP ERIN TORONTO!

The Max and Beatrice Wolfe Children's Centre would like to invite children between the ages of 6-17 to attend Camp Erin Toronto which will be held from June 4-6th in Muskoka. Camp Erin is for youth who have experienced the death of a parent or sibling or custodial grandparent. There is absolutely no cost for children to attend the camp. Last September Max and Beatrice Wolfe Children's Centre held their very first Camp Erin Toronto and it was an incredible experience for all involved!

If you are interested please contact: 416-586-4800 ext. 6664. Also, feel free to visit the Camp Erin website at: <http://www.moyerfoundation.org/programs/CampErin.aspx>