

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

Many bereaved parents seek to make meaning out of their loss by helping others.

This preliminary inventory shows the contributions of 20 parents in the following areas:

- ❖ Advocacy
- ❖ Direct Service to other families
- ❖ Education
- ❖ Fundraising
- ❖ Policy and program development
- ❖ Research.



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

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Advocacy



- ❖ Toronto Central Palliative Care Network
- ❖ Media interviews (CITY TV, Toronto Star)
- ❖ Guest speaker 20th anniversary of Palliative and Bereavement Services
- ❖ Perspectives of a mother on “Now I lay me down to sleep” legacy photography.
- ❖ Interview for NFB film *Griefwalker*

Specific issues

- ❖ Wayfinding sign for Palliative Care Service offices
- ❖ Establishing hospital memorial service
- ❖ Celebration of deceased in Sick Kids Atrium
- ❖ Advocating for more Foundation support of palliative care service events



Photo by Heather Rivlin

Direct service

- ❖ Support to other families
- ❖ Memorial Events
- ❖ Annual b.r.a.i.n.child conference
- ❖ Gift & Estate Planning Team at Sick Kids Foundation
- ❖ Bereaved Parents Network
- ❖ Max & Beatrice Wolfe Centre
- ❖ Blogs e.g. <http://sashabella.blogspot.com/>
- ❖ Facebook pages and websites e.g. <http://www.foreverheart.ca/angel-guestbook>

Legacy creation

- ❖ “I Will Hold You In My Heart Forever” a baby book for little angels by Michelle Murray.
- ❖ “Forget me not” flower arrangements for bereaved parents.



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Policy & program development

- ❖ Family Centered Care Advisory Council
- ❖ Advisory board of TRAC-PG
- ❖ Sick Kids Bereavement Task Force
- ❖ NICU parent council
- ❖ Families as Partners in Patient Safety
- ❖ Care for Kids fund
- ❖ Max and Beatrice Wolfe Centre (Mount Sinai)

Research

- ❖ Parent Liaison, TRAC-PG
- ❖ Study participants
- ❖ Grant review committee members
- ❖ Co-investigators/co-authors
- ❖ Reviewers



Fundraising

Memorial donations

- ❖ direct donations to NICU, Palliative Care Bereavement Service, Expressive Therapies, Reading Room, brain tumour research and undesignated donations, applied to high priority needs.

In-Kind Donations

- ❖ Trac-pg.ca
- ❖ "I Will Hold You In My Heart Forever:", a baby book for little angels
- ❖ Song written to benefit NICU bereavement program

Special Events

- ❖ Wyatt's Warriors (Labatt Family Heart Centre)
- ❖ Meagan's Walk (brain tumour research)
- ❖ Josiah's Walk (neo-natal intensive care, St. Joseph's Hospital, London)

Tribute Named Funds

- ❖ The Sasha Bella Fund
- ❖ Paige Berry Memorial Fund

Endowment Funds



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Education at Sick Kids

- ❖ Medical, nursing and OT students
- ❖ PERLS- Paediatric Residents Learning Seminars.
- ❖ staff training in ICU, Cardiac Critical Care Unit, Heart Centre interprofessional practice days, RTS (Resolve Through Sharing Perinatal Grief Training
- ❖ Palliative Care Symposium
- ❖ Support to Sick Kids Foundation staff working with bereaved families
- ❖ Development of training documents and resources
- ❖ Advise staff about helpful palliative/end of life family resources



Community Education

- ❖ Sick Kids palliative care training course
- ❖ Inter-professional Practice Education Week
- ❖ Canadian Association of Paediatric Health Centres
- ❖ Perinatal Bereavement Conference
- ❖ National Palliative Care Week
- ❖ Canadian Palliative Care Conference
- ❖ Canadian Family Advisory Network
- ❖ St. Joseph's Hospital London "Creating Legacies for Children with Now I Lay Me Down To Sleep remembrance photography."
- ❖ London Children's Hospital Palliative Care Symposium
- ❖ Institute for Family Centred Care Palliative Care



Discussion and future directions

- ❖ Many parents not aware of the range of volunteer and donor options available.
- ❖ These kinds of opportunities could be more actively shared with grieving parents to help them develop coping skills.
- ❖ It would be useful to investigate the impact of participating in specific types of fundraising and volunteer work on coping with grief.

Contributors

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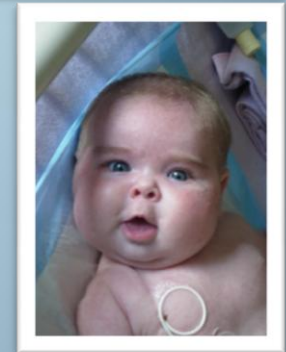
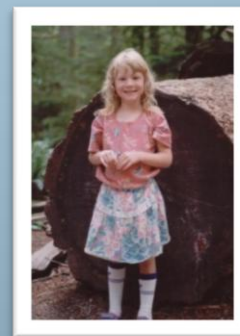


Photo by Heather Rivlin



For Natalie, Brendan, Sasha, Josiah, Paige, Tyler, Elric and Meagan.