

Pediatric Oncology Palliative Care Newsletter

Conferences --- Education

May 2006 - Rouge Valley Centenary (Scarborough) 6 module course, "Pediatric Hospice Palliative Care: Offering Excellence." Contact Maria Rugg (maria.rugg@sickkids.ca) for details.

June 7, 2006 - Kitchener-Waterloo Regional Palliative Care Conference to be held in Kitchener. Contact Patti Bambury (patti.bambury@grhosp.on.ca) for details.

June 21 -23, 2006 - [3rd International Cardiff Conference 2006 Paediatric Palliative Care](#)

Monthly -Transcontinental telehealth educational rounds specific to paediatric palliative care. Contact Maria Rugg (maria.rugg@sickkids.ca) for details.

Dr. Louise Coulombe has created web-based education modules for Pediatric Palliative Care. The Pediatric Community Palliative Care Modules are part of the Spectrum Series and can be viewed on-line at the Community Palliative Care Network (CPCN) at the following WEB address:

<https://www.cpcndb.org/Seminars/CHEO>

Username: Guest

Password: 'Seminars' (capital S!)

Developing a Pediatric Palliative Care Network

New Expert Contact List on the POGO website

<http://www.pogo.ca/care/palliative-care/care-expert/>

The Hospital for Sick Children The Palliative and Bereavement Care Service (PCBS) Highlights

- Created in 1986 as one of the first hospital-based paediatric palliative care services in North America.
- Variety of diagnoses: 15 patient referrals in 2000; 68 referrals in 2003; 94 referrals in 2004.
- Establishment of a comfort care cart for our paediatric medicine floor, funded by a recent donation from the Children's Wish Foundation.

An Introduction to Our Team

- Dr. Christine Newman (0.5 FTE palliative care physician)
- Maria Rugg (full time clinical nurse specialist/nurse practitioner)
- Laura Beaune (0.8 FTE coordinator/social worker)
- Ruth Roberts (an externally funded music therapist)

We are closely affiliated with palliative and bereavement coordinators in the hospital's CCU (Vera Nenandovic) and NICU (Lori Ives-Baine), and draw on clinical expertise from chaplains, social workers, physicians, a therapeutic clown and discharge planners from across the hospital and the community.

What We Do

We work in collaboration with primary health care teams at HSC or within the community to provide the following:

- Consultation/shared care regarding pain or other symptom management issues
- Consultation/shared care around discharge planning of the palliative care patient
- Consultation to primary care teams regarding difficult conversations, decision-making, care for the caregiver support
- Consultation/shared care regarding palliative, end-of-life and bereavement care
- Home visits in the Greater Toronto Area or within a 90-minute drive of HSC to support a child's discharge home, medical crisis, death at home and/or after care/bereavement care.
- Participation in program development, policy/advocacy and research initiatives

Community Highlights

In spring of 2005, the Palliative Care and Bereavement Team hosted a pre-conference workshop at 15th Annual Provincial Conference on Palliative and End-of-Life Care (Toronto) called "Adding Life to a Child's Time: Paediatric Palliative Care Issues and Skills". A portion of this presentation was published in *Rehabilitation & Community Care Medicine* this fall.

For more information about the Palliative and Bereavement Care Service at SickKids, please refer to our website:

www.sickkids.ca/palliativecareforhcp (our site for health care professionals) and www.sickkids.ca/palliative (our site for families).

Kitchener-Waterloo Region Pediatric Hospice Palliative Care Committee

- Forming working groups to develop a protocol for pediatric expected deaths that will be honoured and supported in all settings in Waterloo Region. This group will include members of both the Catholic and Public School Boards, EMS, CCAC, ethics, pediatric clinic nurse, pain and symptom manager, nursing agency nurses and a pediatrician.
- POGO Interlink nurse role has become a very valuable service in the Kitchener-Waterloo Region.

Some notable players in Pediatric Palliative Care in Ontario

Dr. Christine Newman has a new role as Co-Director of the Max and Beatrice Wolfe Children's Centre, affiliated with the Temmy Latner Centre for Palliative Care, in addition to her role as a palliative care physician at HSC. This new program will focus on providing interdisciplinary care for the dying child at home and for children of dying parents. Thanks to **Maria Rugg** for her tenacity, her hard work and her never ending generosity to the children and families that she has cared for over the years. Maria has been the heart and soul of the HSC team since her arrival to palliative care in 1993. **Dr. Mike Harlos**, Winnipeg, completed an 8-week pediatric palliative care fellowship at HSC.