



Net News

WELCOME

Welcome to the first issue of the CNPCC Net New! The CNPCC Net News is the quarterly newsletter of the Canadian Network of Palliative Care for Children! This newsletter's aim is to provide information about pediatric palliative in Canada. The hope is that a variety of information can be shared, from clinical information to stories of parents or siblings.

The newsletter will feature a variety of areas

which include:

- **What's New**—in research, education or practice
- **Resources**—information on books, websites, policies, etc.
- **Case Study**—submissions about case experiences
- **Parent Submissions**
- **Kid's Korner**—for children receiving services or siblings to express themselves

We welcome submissions, which can be sent to: newsletter@cnpcc.ca

Your assistance is needed to let others know about this newsletter and the CNPCC. If you could forward this to your colleagues in pediatrics it would be greatly appreciated. The newsletter is also available on the CNPCC website:

<http://cnpcc.ca>

What is the CNPCC?

The Canadian Network of Palliative Care for Children (CNPCC) has developed out of the Pediatric Hospice Palliative Care Special Interest Group (SIG) of the Canadian Hospice Palliative Care Association (CHPCA). It remains under the umbrella of the CHPCA, and reports to its Executive Director as described in the CNPCC Terms of Reference.

It is envisioned that the CNPCC will be comprised of a broad group of individuals involved in palliative and end-of-life care of children, including those who may see palliative care in general as being rather peripheral to their primary clinical field, such as pediatric cardiology, nephrology, respiratory, neurology, genetics, and specialties related to metabolic diseases.

The formation of a network whose focus is to address issues unique to palliative and end-of-life care for children will facilitate standards development, advocacy, and education, perhaps raising the profile of pediatric palliative care into the awareness of the broad group of caregivers mentioned above, and of the community in general.

CNPCC Net News

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Special points of interest:

- ☺ This is our first issue—we are glad you are reading!
- ☺ Discover what the CNPCC is all about!
- ☺ Find out about the folks who make the CNPCC happen!

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Meet the Executive of the CNPCC

CO-CHAIRS

Filomena Nalewajek

Prior to her appointment as Executive Director in March 2003, Filomena was Director of Programs and Services, a position that gave her the lead responsibility for Canuck Place's clinical programs. Filomena has a Bachelor's and a Master's degree in nursing, and has focused on pediatrics and palliative care for more than 25 years. Besides her clinical nursing experience, she has taught at several universities in both British Columbia and Alberta and currently holds an adjunct appointment with the Faculty of Nursing at the University of British Columbia. She is an Executive Committee member of the Children's International Palliative Project - a committee of the National Hospice Palliative Care Organization. She is co-chair of the Canadian Network of Palliative Care for Children, an arm of the Canadian Hospice Palliative Care Association. Filomena is also on the Board of the BC Hospice Palliative Care Association.

Mike Harlos

Michael Harlos, MD, Medical Director of Winnipeg Regional Health Authority Palliative Care and of St. Boniface Hospital Palliative Care, has been a palliative care physician for 14 years. He is also section head of Palliative Care in the Department of Family Medicine at the University of Manitoba, where he is an Associate Professor. Dr. Harlos is the Physician Consultant for the Canadian Virtual Hospice. He is Co-Chair of the Canadian Network of Palliative Care for Children, and developed and maintains their web site. He has also developed and maintains the site <http://palliative.info>, a site for palliative care links and resource material.

Mike is currently in the role of co-chair in an acting capacity while Laura Beaune is on maternity leave.

NORMS OF PRACTICE

Linda Côté-Brisson

My specific role on the CNPCC Executive is to link with the work on palliative care norms, being done presently by the Canadian Council on Health Service Accreditation. I think that it is quite important, as do my colleagues, that the palliative care norms used to accredit our different pediatric institutions reflect pediatric palliative care specificities. This also seems to be a wish of the CCHSA.

I am a grandma to an exuberant 4 and a half year old, Juliette as well as a pediatric oncologist, presently on sabbatical, training in palliative care. While working for the Ministry of Health and Social Services in Quebec I participated in the development of the province's palliative care policy that was published in May 2004. This policy was informed by a paediatric working group. At the present time, as a follow up to this work, the group including myself, is looking at developing/adapting standards for pediatric palliative care that could possibly be adopted province wide. I also am on an advisory committee to the Institute of Public Health in Québec that is looking at palliative care indicator development for the province. I love photography, walking, reading. I am also an information addict that would be very stressed if the net was not there. I hope, that together, we will be able to forward pediatric palliative care and make it so that the kids and their families get the best possible care .

Visit the CNPCC
online at:

<http://cnpcc.ca>

It is worth a look!

EDUCATION

Maria Rugg

Maria Rugg graduated from the University of Windsor with a Bachelor of Science in Nursing with Honours in 1990. She obtained her Master's of Nursing Science, Acute Care Nurse Practitioner in Pediatrics from the University of Toronto in 2001. She has just recently achieved national certification as a Hospice Palliative Care Nurse in Canada(2004). Presently she works as Acute Care Nurse Practitioner for Pediatric Palliative Care Program at The Hospital For Sick Children. She completed training in the EPEC Curriculum 2000 and EL-NEC Curriculum 2002. She began work in 1994 as the Palliative Care Coordinator at The Hospital For Sick Children and within this role has lead many initiatives including: end of life care policy development ; bereavement and palliative care standards and palliative care program planning and development. As a member of the executive I will be representing the education sub group of the executive and work as a member of a hospital program.

RESEARCH

Kimberley Widger

Kim has recently become the chair of the research working group within CNPCC. She has been the Clinical Nurse Specialist and Coordinator of the Pediatric Palliative Care Service at the IWK Health Centre in Halifax for nearly 6 years. She completed her Master of Nursing at the University of Calgary in 1996 focusing on families experiencing the death of a child. She is currently an Adjunct Professor with Dalhousie School of Nursing. She is currently the PI for the Pediatric Palliative Care Surveillance Pilot Project funded by CIHR's Palliative Care Pilot Project Grants. She is also completing a survey which asked bereaved parents to evaluate the end-of-life care that their child received.

MEMBER AT LARGE

Roberta Woodgate

Dr. Roberta L. Woodgate's background is in the area of pediatric nursing. Presently she is an Assistant Professor in the Faculty of Nursing, University of Manitoba. She is the recipient of a Canadian Cancer Society Research Scientist Award (2004-2010) and in 2004 received the Dorothy J. Lamont Scientist Award, a joint National Cancer Institute of Canada and Canadian Institute of Health Research (CIHR) award for the highest-ranking scientist in the Behavioral/Psychosocial/Cancer Control Research Scientist Category. Her research focuses on children and youth with cancer and other life-

threatening, terminal, or chronic illnesses. She is an expert in researching the perspectives of children and youth. Presently she is the Principal Investigator (PI) for several CIHR funded studies including: Development and validation of a computer videogame for self-assessment of meaning-centred symptom experiences by children with cancer; and Parents' and children's decisions and experiences in childhood cancer research studies. She is also in the process of conducting a multi-site national study that focuses on how families transition from diagnosis through the bereavement stage of childhood cancer. As the PI and in collaboration with researchers at the Mayo Clinic (Rochester, MN), she is developing an international research project that focuses on health professionals' perspectives of the transition process in pediatric end-of-life care. She has received two writing awards from the Association of Pediatric Oncology Nursing. In 2004 she was an invited keynote speaker for the SIOP- In-

FAMILY REPRESENTATIVE

Honna Jones-Hodder

Honna Janes-Hodder joined the CNPCC executive committee in 2004 as its Family Representative. Her experience in pediatric palliative care began when her seven-year-old son, Matthew, received end-of-life care in 1997.

Honna has been involved in patient advocacy for more than a decade. In the past, she has worked as a Patient Advocate with the Children's Cancer Group (CCG), a member organization consisting of pediatric oncologists and researchers from Canada, the USA, and Australia. She has worked on various projects with the Canadian Hospice Palliative Care Association (CHPCA), both at the provincial and national level. She recently sat on an advisory committee with CHPCA to consider the legal, moral and ethical issues confronting informal caregivers in Canada. She is the co-author of *Childhood Cancer: A Parent's Guide to Solid Tumor Cancers* (1999 [2002] Sebastopol, CA: O'Reilly & Associates).

Currently, Honna is a graduate student in the Department of Sociology at Memorial University of Newfoundland. Her undergraduate honors thesis, based upon primary and secondary data, researched palliative care in rural Newfoundland and Labrador to illustrate differences among social groups in their capacity to access quality end-of-life care. She expects to complete her Masters degree in early 2005. Honna lives in Paradise, Newfoundland. (who knew that Paradise existed in Canada, of all places???)

**Want to contribute
to future
newsletters? Just
send an email to:**

newsletter@cnpsc.ca

It's that easy!

CHPCA REPRESENTATIVE

Sharon Baxter

Sharon Baxter is currently the Executive Director of the Canadian Hospice Palliative Care Association (CHPCA). Sharon holds a Masters of Social Work degree in Public Policy and Administration and has worked on national health policy for twelve years.

Sharon is the co-chair of the National Strategy on Palliative and End-of-Life Care Coordinating Committee as well as co-chair of the Public Information and Awareness Committee. Sharon sits on many national committees and coalitions looking at End-of-Life care issues specifically around health policy.

The Canadian Hospice Palliative Care Association is the secretariat for the Quality End-of-Life Care Coalition, a coalition of 29 national groups advocating for a better response to end-of-life programs and services. It is through these partnerships that quality end-of-life programs and services advocacy has been so successful.

Sharon Baxter was previously the Executive Director of the Canadian AIDS Society (CAS). Sharon worked for CAS for seven years and was involved in both domestic and international HIV/AIDS work.

Sharon is often invited to speak on advocacy, health policy, HIV/AIDS and hospice palliative care issues. Sharon continues to be a strong advocate on health and social policy issues at the national level.

CO-CHAIR—Maternity Leave

Laura Beaune

Laura has a varied social work background which has included clinical service with children, couples and families, child protection, children and adolescent groups, trauma and adjustment counselling with children with chronic health conditions/traumatic injuries, administration, advocacy and social sciences research. Laura started her career in community work after receiving her Bachelor's of Social Work/Bachelor's of Sociology at McMaster University in 1985. She has worked in the field of domestic violence awareness and prevention and in child protection, intake and family services with the Peel Children's Aid Society.

Laura completed her Master's of Social Work at the University of Toronto and began a long career with The Hospital for Sick Children in 1991. She has provided clinical service to children and families in trauma, the burn unit and the craniofacial program. She also provides practicum placements for Master's level social work students from the University of Toronto and Yeshiva University and has supervised over 10 Master's graduates. Laura has an appointment with the Faculty of Social Work, University of Toronto as an Adjunct Practice Lecturer.

More recently, Laura accepted a consultant position during the hospital's strategic transformation and redesign process. She returned to the University of Toronto in 1996 to

complete a 2 year diploma in applied social sciences research. Laura has also worked as Research Project Manager with the Department of Social Work, HSC as well as a clinical researcher with the Centre for Craniofacial Care and Research where she conducted several funded studies, including an HSC Seed Grant. Laura is currently in the process of publishing 2 of these studies with the Cleft Palate-Craniofacial Journal.

Currently, Laura has been in the role of the Palliative and Bereavement Care Coordinator at HSC since August 2002. In addition to providing clinical consultation, Laura has an interest in education, research and advocacy and is very involved in regional, provincial and national palliative care initiatives. Laura has collaborated on 4 separate research proposals (2 in collaboration with partners across the country) that have been submitted to the CIHR 2003 call for Palliative/End of Life Care and SARS RFA's.

Laura has also had a long history of volunteerism with Camp BUCKO, a camp for children with burn injuries. She currently holds the position of Vice President and Chair of the Quality Management/Volunteer Committees.

Suggestions for the title of this newsletter are welcome!

Email your ideas to:

newsletter@cnpcc.ca

Newsletter Editor:
Simone Steneke

So those are the members of the executive! They are addressing the issues unique to pediatric palliative care here in Canada! Thanks for the great work!