



Net News

CHPCA Publishes National Norms of Practice for Pediatric Hospice Palliative Care

The Canadian Hospice Palliative Care Association (CHPCA) is pleased to announce the publication of *Pediatric Hospice Palliative Care: Guiding Principles and Norms of Practice (2006)*.

In a joint project with

the Canadian Network of Palliative Care for Children (CNPCC), and in partnership with Health Canada's Secretariat on Palliative and End-of-Life Care, national consensus was reached on guiding principles and

norms of practice for pediatric hospice palliative care.

Based on foundational work completed by the Pediatric Hospice Palliative Care Committee of

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New Emerging Team (NET): Transitions in Pediatric Palliative and End-of-Life Care

Since receiving funding in 2004 from the Canadian Institutes of Health Research, the NET has been busy forging new collaborations, training students, conducting pilot research, writing grant applications, and holding a workshop, among many other things.

The five NET Investigators are: *Dr. Hal Sinden*, University of British Columbia/Canuck Place Children's Hospice; *Dr. Rose Steele*, York

University; *Dr. Betty Davies*, University of California San Francisco; *Dr. Lynn Straatman*, University of British Columbia/St. Paul's Hospital; and *Dr. Susan Cadell*, University of British Columbia. The NET Research Coordinator is *Carly Fleming*.

The main goal of the NET is to create knowledge and evidence so children with life-limiting conditions - and their families - get the best care possible. In order to achieve this goal, re-

search is being conducted that addresses three main themes. Highlights of research activities within each of the themes are described below.

1. Biomedical and Clinical Indicators

Workshop: *Nutritional Failure at End of Life in a Pediatric Population*. Held Feb. 23 & 24, 2006 in Vancouver, BC.

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CNPCC Net News

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Special points of interest:

- ☉ Norms of Practice for Pediatric Hospice Palliative Care
- ☉ NET Update
- ☉ Pediatric Hospice in Calgary

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New Emerging Team (NET)

2. Families

Successful CIHR Operating Grant: *Caregiving Parents of Children with Life-Limiting Illnesses: Beyond Stress and Coping to Growth*. Investigators: S. Cadell, H. Siden, B. Davies, R. Steele, L. Straatman, D. Hemsworth, S. Liben.

3. Health Services

CIHR Operating Grant Submitted: *Process Maps in Pediatric Palliative Care: A Tool for Understanding the Flow of Patients and Families through the Health Care System*. Investigators: H. Siden, M. Puterman, S. Cadell, H. Krishnan, M. Nagarajan.

If you would like any further information about the NET or its activities, please send an e-mail to pallpedsnet@cw.bc.ca.

Submitted by:
Carly Fleming, M.Ed.
Clinical Research Coordinator
New Emerging Team (NET) Transitions in Pediatric Palliative and End-of-Life Care

New Textbook - Pediatric Palliative Care

Goldman, A. Hain, R., & Liben, S. (Eds) (2006). *Oxford Textbook of Palliative Care for Children*. Oxford University Press: New York, New York.

Development of a Pediatric Hospice in Calgary

The Palliative Care and Grief Support Team at Alberta Children's Hospital is pleased to be moving ahead with the development of a pediatric hospice. With a large donation from the Calgary Flames and support from the Calgary Health Region and the ACH Foundation, "Flames House" is projected to open in 2007. Currently, a search for real estate in the hot Calgary market is underway. It is hoped that an acreage site will be found within a few kilometers of the new Children's Hospital. The seven-bed hospice will provide a much-needed site for respite, transition care, and end-of-life care for children with life-limiting illnesses.

Submitted by:
Dr. Sharron Spicer
Division Chief, Pediatric Palliative and Respite Care
Alberta Children's Hospital


Now I Lay Me Down to Sleep

My name is Heather Rivlin, and as the Toronto regional coordinator for the "Now I Lay Me Down to Sleep" program, I would like to take a moment to introduce myself, and the services that our organization provides.

Now I Lay Me Down to Sleep is a charitable, non-profit organization whose membership is comprised of professional photographers throughout Canada, the United States, and the United Kingdom. As professional photographers, we volunteer our time and services to provide families experiencing neonatal loss with the opportunity to have heirloom portrait photographs of their loved one, either prior to their passing, or shortly after. In order for infants to qualify for this program, they must have reached at least 20 weeks gestation.

There is absolutely no cost to the families for this service.

While each photographer uses his/her discretion about what additional services/items they are willing to provide, each photographer has agreed to provide at the very minimum a portrait session, and a complete set of negatives (either digital or film) so that the family may make as many additional copies as they require. In many cases, photographers, like me, are also providing families with a DVD slideshow of their images set to music, to further preserve these precious memories.

We know that neonatal death is sometimes inevitable, and unfortunately the demand for our services has the potential to be high. I have been busy building a team of regional photographers to assist in our efforts to provide families in the Toronto re-

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CHPCA*

British Columbia, B.C. Children's Hospital, Canuck Place Children's Hospice, and the Pediatric Hospice Palliative Care Standards Committee at the Hospital for Sick Children in Toronto, and with a financial contribution of Health Canada, the CHPCA created a draft national pediatric hospice palliative care norms of practice document that was used for the consensus project.

Working in partnership with CNPCC an advisory committee was created to provide input into the development of the national consensus survey. Advisory Committee members included: Filomena Nalewajek, Co-Chair, CNPCC; Mike Harlos, Co-Chair, CNPCC; Kay Johnson; Christine Newman; Christina West; Maria Rugg; Roberta Woodgate and Sharon Baxter, Executive Director, CHPCA.

The project achieved consensus through an on-line consultative process that targeted multiple stakeholder groups including: individuals who specialize in pediatric hospice palliative care including children's hospitals, other pediatric health centres and children's hospices; pediatric health care practitioners, including family physicians and community-based nurses; families and caregivers of dying children; and other interdisciplinary hospice palliative care professionals.

An electronic version of *Pediatric Hospice Palliative Care: Guiding Principles and Norms of Practice (2006)* [*Soins palliatifs pédiatriques: Principes directeurs et norms de pratique (2006) en français*] is available for download from the CHPCA web site. [www.chpca.net] Click on "Marketplace" and then "Hospice Palliative Care Norms of Practice".

For more information please contact Greg Adams at gadams@scohs.on.ca.

Submitted by:

Greg Adams

Administrative Coordinator

Canadian Hospice Palliative Care Association

*An electronic version of
Pediatric Hospice
Palliative Care: Guiding
Principles and Norms of
Practice (2006) [Soins
palliatifs pédiatriques:
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www.chpca.net

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gion with this service. You may have seen the article in the Toronto Star from March 2006, or the news story on Global Na-

tional in April 2006 discussing my work with Toronto area families through this program. If you did not see these media pieces, and would like to, please let me know, and I can make them available to you.

If you know a family who meets the criteria for this service, who you feel would benefit from the services that we offer, I would encourage you to contact me, as the regional co-ordinator in order to locate an available photographer. My role is simply to connect families with a photographer, thereby assisting the hospitals, hospices, and health care workers from having to make several phone calls. As a main contact person, you simply need to contact me, and I will fan out calls to local photographers and locate someone who is willing and able to assist. The list of Toronto-area photographers is available on the website at www.nowilaymedowntosleep.org, however, it is easiest for all those involved to have one main contact person to call when services are required. That way, you can get back to caring for those you serve knowing that my team is working to find a photographer for you to meet this family's needs.

If you have any questions, please do not hesitate to contact me at (416) 782-6482 or info@heatherrivlin.com

Submitted by:

Heather Rivlin—Photographer

www.heatherrivlin.com



**7th INTERNATIONAL
SYMPOSIUM ON
PEDIATRIC PAIN**

**June 25-29, 2006
Vancouver, BC**

www.meet-ics.com/ispp2006

Hosted by the **Canadian Pain in Child Health Society for the Special Interest Group on Pain in Childhood of the International Association for the Study of Pain.**

"The **ISPP 2006 Education Day** will focus on serious gaps between recent advances in understanding and controlling pain and inadequate application of best practices in clinical and institutional settings. This Education Day should appeal to new and seasoned practitioners committed to initiating change and breaking down barriers working with children and their families, other professionals and organizations in need of change. The **ISPP 2006 Education Day** is held prior to the ISPP Conference and is designed to complement the larger conference program by providing a venue for putting new knowledge into practice.

In sum, the **ISPP 2006 Education Day** will focus on the process of ap-

plying new theoretical and evidence-based knowledge to develop concrete and action-oriented strategies to initiating change in the Pediatric pain management at all levels, patient, family, institutional and societal."

-ISPP Website

**6th International
Forum on Pediatric
Pain**

This Forum will be held in beautiful White Point, Nova Scotia, from October 12-15, 2006. The title of the meeting will be "Pediatric Pain: A Clinical Casebook" and will consist of an innovative series of evidence-based patient case discussions on selected themes in pediatric pain, chaired by invited experts in the area. We believe this approach will enhance the integration of science and clinical practice.

We are currently seeking submissions of cases for oral and poster presentation at the upcoming meeting.

We look forward to seeing you at White Point in the fall of 2006!

Christine Chambers, Allen Finley, & Patrick McGrath

Newsletter Editor:
Simone Stenekes

**16th International
Congress on Care of
the Terminally Ill**

The **16th International Congress on Care of the Terminally Ill**, taking place in Montreal, Canada, September 25-29th, will give healthcare professionals, therapists, volunteers, and all those involved in care for the dying the opportunity to renew themselves as providers of care and obtain the inspiration that will help shape the palliative care of the future. There is a special session on pediatric palliative care that may interest some of you.

**Tuesday, September 26
9:00 - 17:30**

**UNDERSTANDING WHAT
FAMILIES WANT AND WHAT
CHILDREN NEED: PEDIATRIC
PALLIATIVE CARE RESEARCH
BRINGS US CLOSER**

Organizer and Chair:

Stephen Liben, *Montreal Children's Hospital, McGill University*

What have we learned in our daily practice that can help us do things better, both for our own well being as well as for the children and families in our care? This all-day seminar will feature presentations from international researchers in pediatric palliative care that will serve as a catalyst to discussion and reflective-practice small group work.

For further information:

<http://www.pal2006.com/>