



Net News

PROGRAM HIGHLIGHT
Pediatric Palliative Care Program
Capital Health (Edmonton)

CNPCC Net News
Volume 3, Issue 3
November 2007

Clinical

New nurse coordinator is Tara Wren, who many of you met in Toronto. She has previously worked both in Children's Services- Homecare, and as an inpatient nurse in pediatric oncology, so is the perfect fit! Faye Schwab has been the full-time grief counselor for the Stollery Children's Hospital for just over a year, and is also



very gifted. She sees a lot of parents while they are in hospital, and does home visits as well. She runs the bereavement follow-up program, and facilitates 3 grief groups for parents annually, which have received great evaluations.

Our program was recently featured in the Edmonton Journal

<http://www.canada.com/edmontonjournal/news/story.html?id=9a9a680e-e9cf-403f-8061-6c9fedeb06aa>

Again, I can't say enough about the role of Children's Services Homecare *continued on page 2....*

- Special points of interest:**
- Edmonton Program Highlight
 - New IPCN Website Launched

CNPCC MEETING AT CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION CONFERENCE

The Canadian Network of Palliative Care for Children met at the Canadian Hospice Palliative Care Association (CHPCA) conference in Toronto on November 4th. There were over 40 people in attendance, with representation from Canada

and the United States. One of the highlights was the launching of the Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice. The document is available in paper format, CD-ROM, and can also be downloaded on the

CHPCA website (www.chpca.net).

The second portion of the meeting was coordinated by the PedPal-Net. Several NET research trainees presented their proposed *continued on page 3....*

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Program Highlight Edmonton

in being able to provide expert palliative care at home in the CH region. Without their 24/7 access, we would not be able to do a lot of what we do in the community.

Education

A 3rd year subspecialty resident, Mark Belletrutti, is finishing his pediatric hematology/oncology training and is doing a 3rd year in pediatric palliative care with us, in combination with his Master's of Epidemiology and adult palliative care training. An increasing number of residents and medical students are spending time with our program over the past few years.

Research

Current projects:

- 1) ketamine study in oncology patients as adjuvant to opioids
- 2) massage study for inpatient pediatric oncology patients
- 3) parent-delivered massage therapy to pediatric oncology patients
- 4) methadone for children with advanced cancer
- 5) needs assessment for hospice services from bereaved and prospective parents' point of view
- 6) predictors of severe neurological disability or death in pediatric/adolescent hanging injuries
- 7) national survey of pediatric intensivists, neonatologists and pediatricians re: attitudes and decision-making pertaining to withholding or withdrawing artificially provided hydration and nutrition in infants and children (Dr. Belletrutti, PI)

Submitted by :
Dawn Davies - Physician

NEW IPCN Website Launched

The International Children's Palliative Care Network (ICPCN) launched its website to coincide with the global celebrations and activities for World Hospice and Palliative Care Day (6 October 2007).

The new website www.icpcn.org.uk aims to bring together all agencies and individuals working with children's palliative care across the world. This new online forum will help to increase awareness and lobby for the global development of dedicated children's palliative care services. It's hoped that the website will also provide an online global 'one stop shop' for information; enable the sharing of expertise and information between children's palliative care practitioners; and increase the international evidence base for children's palliative care.

www.icpcn.org.uk will provide an online forum for ICPCN members to exchange information, news, events, research and good practice. The website has been designed to enable practitioners to post their own children's palliative care news from anywhere in the world and we would encourage you to use this facility. It's simple to navigate and easy to upload your own country's news, research and developments. You can also publicise your own local events, conferences and seminars. Just follow the website links - it's a great way to get some free publicity and share your own news with the rest of the children's palliative care world.

Anyone with an interest in palliative care can join ICPCN for free and start sharing information, so please let your colleagues know. The site also features an "International Directory" which provides contact and service information for children's palliative care agencies and individuals working in the field. There are currently a few teething problems with the members information on the site but this will be fixed as soon as possible. Once the site is launched, it will host a dedicated "icpcn forum" to enable members to discuss and debate the latest developments in children's palliative care. We would be grateful if you are able to publicise the website through your own networks, newsletters or websites. Please do feel free to link your site to ours. The URL is <http://www.icpcn.org.uk>
We look forward to hearing your feedback on the website.

Sally Wain-Heapy
On behalf of ICPCN

Sally Wain-Heapy
Communications Assistant, ACT

Roger's House Interdisciplinary and Inter-Organizational Mentorship for Pediatric Palliative Care Initiative 2007

In the spring of 2007 Roger's House, one of only a few pediatric hospices in Canada, partnered with 3 other palliative care agencies from across Canada to share knowledge and skills about caring for children with life limiting illnesses and their families. Roger's House's professional staff, volunteers and community partners were mentored by the Hospice at May Court (Ottawa), the Canuck Place Children's Hospice (Vancouver) and the IWK Halifax Pediatric Palliative Care Team. This initiative was funded through the Inter-professional Mentorship, Leadership and Coaching (IMPLC) Fund sponsored by the Ontario Ministry of Health and Long term Care, Nursing Secretariat.

The goals of the initiative included: enhancing clinical skills of professionals, clarifying roles and responsibilities, enhancing collaborative practice and communication between team members, improving program processes, structure and procedures and developing rela-



tionships among and between like colleagues to enhance sharing of clinical experience and research ideas. These goals were derived from the Roger's House Inter-professional and Inter-organizational Mentoring Needs Assessment as well as the Roger's House Program Improvement and Feedback Survey (fall 2006).

One hundred and seventy-one participants (49 mentors and 118 mentees) attended a total of 12 days of mentoring in 4 locations across Canada. Participants logged in over 1121.5 hours of education and mentoring activities. Participation was interdisciplinary in nature and included professionals from the nursing, medi-

cine, pharmacy and allied health disciplines as well as numerous volunteers.

Satisfaction of participants was overwhelmingly positive. Highlights included collaboration, collegiality, team building and validation of shared practices. These elements were experienced and have set the stage for future partnerships.

We wish to thank the Hospice at May Court, the Canuck Place Children's Hospice and the IWK Halifax Pediatric Palliative Care Team for sharing their knowledge, skill and expertise in caring for children with life limiting illnesses and their families with the Roger's House Pediatric Hospice professional staff, volunteers and partners.

Submitted by:

Lynn Grandmaison Dumond

Advanced Practice Nurse

CHEO Palliative Care Program

CNPCC Meeting at CHPCA Conference

research or research in progress. The results of the delphi process undertaken to identify national research priorities for pediatric palliative care was also presented.

For further information or updates on the research that is happening with the PedPalNet, see their website at <http://www.pallpedsnet.ca>

Congratulation to Mike Harlos, the 2007 recipient of the Eduardo Bruera Award, given by the Canadian Society of Palliative Care Physicians to a physician who demonstrates excellence in the field of palliative medicine.

PEDIATRIC PALLIATIVE CARE RESOURCES

It was suggested at the conference in Toronto that the newsletter provide some information on pediatric palliative care related resources that are available both nationally and internationally. So,

here is a new little section that you will find in the next few issues. If you have some suggestions about resources to include, please share them with me, I'm always looking for things to incor-

porate in the newsletter! If you are feeling particularly helpful, you may even want to write a little summary too!

Email: newsletter@cnpcc.ca

Ian Anderson Continuing Education Program in End-of-Life Care

www.cme.utoronto.ca/endoflife

The Ian Anderson Education Program is a joint project of the Continuing Education, Faculty of Medicine, University of Toronto; The Joint Centre for Bioethics, University of Toronto; and The Temmy Latner Centre for Palliative Care, Mount Sinai Hospital, Toronto.

The program has a total of 13 teaching modules that include powerpoint presentations and a

variety of educational techniques that can be used, including small group problem-based learning, case-based teaching and distance learning.

The twelfth module, entitled "End-of-Life Decision-Making in Pediatric Palliative Care", was developed by Gerri Frager and Yarrow McConnell. It is a great resource that can be adapted to a variety of teaching environments.



www.griefworksbc.com

Griefworks BC exists through a partnership between Children's & Women's Health Centre of British Columbia and Canuck Place Children's Hospice with the main objective of providing grief support to those in need of information and resources. There are separate areas for kids, teens and adults,

so the information is tailored according to the age group. It contains practical ideas about what to do when you are grieving as well as an "Honour Page" to remember people who have died. A great Canadian resource with short articles that you will likely find helpful to use with families.



Pediatric Pain

<http://pediatric-pain.ca>

The Pediatric Pain Research Lab is located in the IWK Health Centre and the Psychology Department of Dalhousie University host this website that includes information on pediatric pain. The site includes the Pediatric Pain Letter, which highlights free, open-access, peer-reviewed commentaries on pain in infants, children, and adolescents, as well as the Pediatric-Pain Mailing List, an international Internet forum for informal discussion of any topic related to pain in children.

Email your suggestions for pediatric palliative care resources to include in the next newsletter!

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