



# Net News

## Making Beautiful Memories

When people ask what we do at end of life at Roger's House we often say, "provide support, assess and treat symptoms", but most of all we "help make beautiful memories".

"How do you do that?" they ask. Our response is "first and foremost we make the most of every day, every moment by focusing on living rather than dying".

Roger's House is a pediatric



Hospice in Ottawa, Ontario that cares for children and youth with progressive life limiting illness and their families and friends. Making memories is an important part of what we do. Stays at Roger's House are orchestrated to enhance liv-

ing at its best. Comfortable surroundings, compassionate staff and volunteers as well as engaging activities help make the best of very difficult times.

Of particular interest to many is the preparation of memory boxes. Ours are generously and beautifully decorated by the Ottawa Valley Painter's Guild. They hold many precious items and mementos; locks of ...continued on page 2

CNPCC Net News

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### Special points of interest:

- Making Beautiful Moments—creating lasting memories at Roger's House
- Upcoming conferences

### Palliative & Bereavement Care Service, SickKids Hospital

## Paediatric Hospice Palliative Care: Offering Excellence Together

November 4th, November 18th, December 2nd, December 16th, 2008

**Description:** This 4 day course will cover a wide range of issues in paediatric palliative care. Topics will include: bioethical considerations, communication, decision making, team dynamics, working with children and families, symptom assessment and

management, end of life care, grief, mourning and bereavement, care for the caregiver, and spirituality

**Course objectives:** The goal of this course is to address a knowledge gap for health care professionals and volunteers by

providing specialized paediatric palliative care education. This is a unique educational opportunity as the course framework was developed by a group of multi-agency, hospital and community interdisciplinary ...continued on page 2

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## Making Beautiful Memories

hair, plaster casts of hands and feet; a favorite piece of clothing and of course priceless photographs.

Many caring individuals facilitate memory making. Recently (August 02, 2008), an article in the Ottawa Citizen by Jessey Bird highlighted the importance of photography at end of life as a memory making activity. The article entitled "Such a Small Moment" describes the volunteer activities of "professional photographers from all over the world who have joined together to provide free, creative, studio-quality photos of infants who have died or are about to die". Many of the professional volunteers belong to Now I Lay Me Down To Sleep Foundation (NILMDS). This foundation administers a network of 5,000 volunteer photographers in the United States and nineteen International countries ( <http://www.nowilaymedowntosleep.org> ).

The article and a touching audio clip speaks for itself and can be found at:

<http://www.canada.com/ottawacitizen/news/story.html?id=b4e1d48f-1ed8-4677-bc89-e848fe7e0e36>

The best to all of you who help make the most of living!

*Submitted by:*

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Advanced Practice Nurse, CHEO  
Palliative Care Outreach Team

Children's Hospital of Eastern Ontario

## SickKids

### Paediatric Hospice Palliative Care: Offering Excellence

health care providers, parents and volunteers which ensures a holistic and systemic approach to the knowledge development and dissemination.

**Target Audience:** The course is designed for all professionals and volunteers who work with and care for children with life-threatening illnesses and their families.

**Location:** The Hospital for Sick Children, Toronto, Ontario

**Organizers:** Palliative & Bereavement Care Service, SickKids Hospital

**Contact:** Sabrina Menezes

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

[newsletter@cnpsc.ca](mailto:newsletter@cnpsc.ca)

## PEDIATRIC CLINICS OF NORTH AMERICA

Check out the October 2007 issue (volume 54, number 5) of Pediatric Clinics of North America. The entire issue is on pediatric palliative care—**13 great articles!**



November 16-19, 2008

Palace Hotel

San Francisco, CA

This year's focus is:

**Innovations in Care: From Policy to Bedside and Beyond**

**Confirmed speakers include:**

**Javier R. Kane, MD** Director, Palliative Medicine and End-of-Life Care Program; St. Jude's Children's Research Hospital

**Myra Bluebond-Langer, PhD** Professor of Anthropology and Director of the Center for Children and Childhood Studies; Rutgers University Camden, NJ

**Terri Pratt, Director**, Division of Integrated Health Systems; Center for Medicaid and State Operations

**Rev. Mpho Tutu, Board Member**, Global AIDS Alliance; Founder and Executive Director, The Tutu Institute for Prayer and Pilgrimage

For further information:

[http://www.chionline.org/events/world\\_congress\\_19th.php](http://www.chionline.org/events/world_congress_19th.php)



## Canadian Hospice Palliative Care Conference

### Congrès canadien de soins palliatifs



Crossing the Bridge to Knowledge & Sharing • Delta Prince Edward  
Charlottetown, PEI Canada • October 26 – 29, 2008

The Canadian Hospice Palliative Care Conference is the foremost national conference in Canada focusing on hospice palliative care. This event provides hospice palliative care professionals, volunteers, and family or informal caregivers with the opportunity to share their experience and expertise on a national platform.

Furthermore, throughout the four days of the conference you will learn about the important issues facing people who work with those who are dying, and you will hear experts in a number of fields, debate and discuss these issues and offer solutions. You will hear both consensus and controversy. You will leave with many answers, and perhaps

some questions you hadn't thought of before.

There will be time scheduled during this event for the CNPCC (a special interest group of the CHPCA) to meet.

For further information see:  
<http://conference.chpca.net/>

## The 7th International Forum on Pediatric Pain: Assessing Pediatric Pain: Current Evidence and Practice

October 2-5, 2008

White Point Beach Resort - Nova Scotia, Canada

The Forum will feature lectures by renowned research faculty, as well as your own peer-reviewed posters. More details about the meeting and the Registration and Information Brochure can be found at: <http://pediatric-pain.ca/ifpp/>  
The deadline for abstract sub-

mission is June 1, 2008. More details about abstract submission are available on the Registration and Information Brochure.

The early registration deadline is July 1, 2008. Register soon! Participation is limited to 150 delegates, and previous meetings have

sold out quickly.

The International Forum on Pediatric Pain is organized by Allen Finley, Patrick McGrath, Christine Chambers and Margot Latimer of the Centre for Pediatric Pain Research of Dalhousie University and the IWK Health Centre.



## 17<sup>th</sup> International Congress on Palliative Care

September 23-26, 2008

Montréal, Canada

Palais des Congrès

The 17th International Congress on Palliative Care, will give healthcare professionals and all those involved in care for the dying the opportunity to renew themselves as provid-

ers of care and obtain the inspiration that will help shape the palliative care of the future.

An all day session focusing on pediatric care, entitled "From the Inten-

sive Care Unit to the Home: An Examination of Hope and Meaning in Palliative Care for Children" will take place on September 23<sup>rd</sup>.

<http://www.pal2008.com>

# PEDIATRIC PALLIATIVE CARE RESOURCES

This section of the newsletter is continuing to highlight pediatric palliative care resources. If you

would like to recommend any resources to include, or if you would like to submit information on a

resource, just email me at:

[newsletter@cnpcc.ca](mailto:newsletter@cnpcc.ca)



The field of paediatric palliative care is a relatively new one in many parts of the world and does not exist in others. Approximately 20 countries have children's hospice and palliative care services. In many cases, people are unconnected and there is a lack of access to good information.

Barriers to quality paediatric palliative care programmes worldwide include a lack of research, appropriate training, awareness and understanding of the rights and developmental needs of children living with

[www.icpcn.org.uk](http://www.icpcn.org.uk)

HIV/AIDS and other life-limiting conditions. Scarcity of resources and inequality of access to available resources exacerbate the problem.

The ICPCN is a network of individuals and organisations all working towards the same goal, so whatever experiences, expertise and available information there is in one organisation, can be accessed and shared by all. It has recently come to an agreement to represent children on the Worldwide Palliative Care Association. Reinforced by these pooled resources, the ICPCN will be looking at practical ways in which it can meet unmet needs over the next three years.

Planned initiatives include:

- ✦ The development of a programme of expertise-sharing through the awarding of scholarships and bursaries.
- ✦ Creation of an inventory of relevant education and training

available worldwide.

Research into the unmet needs of people working in the field leading to a global plan of development and to show gaps to funders.

ICPCN is a "one-stop" information resource which provides information about paediatric palliative care services for professionals, caregivers and families through a website and e-newsletters. It raises awareness of the worldwide need for children's palliative care services, promotes research to support and underpin ICPCN's information and policy work and raises the profile of children's palliative care through advocacy. Membership is free to all individuals and organisations working within the field of palliative care for children. To learn more about us and become a member, visit our website at [icpcn.org.uk](http://icpcn.org.uk) or contact Sue Boucher at [sue@icpcn.co.za](mailto:sue@icpcn.co.za)

*Submitted by: Sue Boucher*

<http://www.bcchildrens.ca/KidsTeensFam/FamilyResourceLibrary/default.htm>



There is a series of 29 pamphlets available on the BC Children's Hospital website. These pamphlets are written for parents. Link to the website above and look under "A-Z

Pamphlets". All of the articles are listed under "Palliative Care - Parenting of a dying child". These are great resources that can be used in your own practice.

The National Hospice and Palliative Care Organization (NHPCO) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end of life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.



[www.nhpc.org](http://www.nhpc.org)



**The Children's Project on Palliative/Hospice Services (ChiPPS)** is working to concretely enhance the science and practice of pediatric hospice and palliative care, and to increase the availability of state of the art services to families. Several

leaders in the field of pediatric palliative care worked collaboratively with NHPCO to develop the Children's Project on Palliative/Hospice Services. The project seeks to make the best-known practices in the field of

pediatric palliative care more widely available to care providers.

NHPCO is pleased to announce the introduction of a Field Review process of the Standards of Practice for Hospice Programs. This field review is beginning with the Pediatric Standards. The Pediatric Standards were developed by NHPCO's Children's Project on Palliative/Hospice Services. This new initiative will allow provider members and interested stakeholders to review and comment on both new and existing standards with the intent to increase awareness, transparency, understanding, and feedback regarding the NHPCO Standards of Practice for Hospice Programs.

## Integrative Pediatric Pain and Palliative Care Online Course

This course, designed for physicians who care for children and adolescents, provides an overview of the neurobiology of pediatric pain within a biopsychosocial framework. It outlines developmental issues re-

lated to pediatric pain as well as strategies for managing acute procedural pain.

For further information, see the UCLA Office of Continuing Medical Education website at:

[www.cme.ucla.edu](http://www.cme.ucla.edu). On the right hand side, click on Integrative Pediatric Pain (listed under Online Courses) where you will find a course description and enrollment information.

## ACT—The Association for Children's Palliative Care

[www.act.org.uk](http://www.act.org.uk)

"ACT - the Association for Children's Palliative Care is a UK-registered charity which is striving to achieve the best quality of life and care for all children and young people with life-threatening or life-limiting conditions and their families.

ACT has three strands to its work:  
1) campaigning for the development of integrated, equitable and sustainable children's palliative care services.

2) working with professionals to

develop best practice and develop and disseminate the evidence base of what works best.

3) empowering and supporting families, including young people, to have a voice in the development of children's palliative care services and providing them with the information they need to access the best care and support.

ACT hosts and administers a mailing list about Paediatric Palliative Care. To join or administer your

PaedPalCare membership, please go to: <http://lists.act.org.uk/mailman/listinfo/paedpalcare>"

ACT also houses the Curriculum in Paediatric Palliative Medicine, which was prepared by the British Society for Paediatric Palliative Medicine and the Association of Children's Hospice Doctors. Also housed in the Training and Teaching area of the website are teaching assessment frameworks to support staff who care for children with complex health needs.