



# Net News

## WHAT'S NEW?

Welcome to the second issue of the CNPCC Net News! The CNPCC Net News is the 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.

This issue is exciting because the CNPCC sur-

vey is now ready and we hope to obtain information from across Canada about who provides pediatric palliative care. See the information below—we need your help!!!!

This issue also contains information about the Pediatric Palliative Care Service in Halifax at the IWK Health Centre. The plan for the newsletter is to highlight programs from across Canada, so that others are informed about who

is doing what, where, and how.

Remember—content for the newsletter is always being sought, so please....share your ideas, clinical scenarios, or stories and creative work of the patients and families you care for.

Don't forget, the newsletter is also available on the CNPCC website:

<http://cnpcc.ca>

## CNPCC NATIONAL SURVEY

The Canadian Network of Palliative Care for Children (CNPCC) is requesting your assistance in completing a survey on the status of pediatric palliative care programs, services and activities in Canada. The CNPCC is a Special Interest Group of the Canadian Hospice Palliative Care Associa-

tion whose focus is to address issues unique to palliative and end-of-life care for children with life-limiting/life-threatening illness. The aim of this network is to facilitate standards development, advocacy, and education, in raising the profile of pediatric palliative care into the

awareness of the broad group of caregivers and of the general community.

The CNPCC developed a questionnaire that will help us identify the status of pediatric palliative care in Canada.

The questionnaire is designed to identify all  
*(continued on page 3)*

### CNPCC Net News

Volume 1, Issue 2

May 2005

### Special points of interest:

- ☺ 1 - The CNPCC Survey on Pediatric Palliative Care is here! We need your help to get it circulated in your province!
- ☺ 2 - There are some neat opportunities in pediatric palliative care....see page 4!

### INSIDE THIS ISSUE

What's New ?	1
CNPCC Survey	1
Program Highlight—The IWK	2
Opportunities in Pediatric Palliative Care	4

# Program Highlight— The IWK Health Centre

The Pediatric Palliative Care Service at the Izaak Walton Killam (IWK) Health Centre in Halifax, Nova Scotia has been in existence since 1995. It started as a consultation service in 1995, and then developed into a formal service in 1998. The team may be small, but their enthusiasm and commitment is evident in the way they care for the children and families throughout the Maritime's. The program currently has a full-time physician and clinical nurse specialist, a half-time bereavement coordinator and an administrative assistant. A fellow is also a part of the team from September 2004-2006. Funding for a second physician to start in the summer of 2005 has been obtained. The team is in the process of recruiting for this position.

Dr. Gerri Frager is a pediatrician and the Medical Director of the Pediatric Palliative Care Service at the IWK Health Centre, as well as an Associate Professor at Dalhousie. She has been here from the beginning, working very hard to promote the philosophy of palliative care within the health care facility and beyond. Gerri worked as a nurse for 9 years, then pursued her medical degree, and completed a year of Internal Medicine. Following her Pediatric Residency, Gerri worked in Newfoundland, including doing fly-in clinics to coastal out-ports. Gerri came to her current position having explored various models of palliative care delivery through a year-long

traveling fellowship covering the US, the UK, and Canada. She then spent just over 2 years as a fellow with the Pain Service at Memorial Sloan-Kettering Cancer Center in New York doing pain and palliative care consultations, teaching, and research. Gerri is a Faculty Scholar Alumnus with the OSI's Project Death in America, which is committed to the goal of improving care at the end-of-life. She is an enthusiastic presenter at regional, national and international conferences and author of publications relating to Pediatric Palliative Care.

Simone Stenekes is the Clinical Nurse Specialist with the team. Simone completed her undergraduate and master of nursing degrees at the University of Manitoba. Her master's thesis focused on decision making in adolescent oncology patients. Simone has worked in pediatric oncology and palliative care and is thrilled to be able to combine her love of the pediatric and palliative care clinical areas in one position. Simone also works for the Canadian Virtual Hospice ([www.virtualhospice.ca](http://www.virtualhospice.ca)), a website for patients, families, health care professionals and volunteers.

Carol Boyd is the Bereavement Coordinator with the service. Carol has her master's degree in social work from Dalhousie and has been working at the IWK

since 2000. She has worked as a Crisis Worker in Emergency, then with the IWK Child Protection Team prior to joining the pediatric palliative care service in 2004. Since beginning with the service just over a year ago, Carol has implemented bereavement support groups for children and adolescents. These groups have been well received and the feedback has been positive.

Marie-Claude Grégoire is a pediatrician undertaking a fellowship at the IWK in pediatric pain and palliative care. Marie-Claude graduated from medical school and received her master's degree in biomedical sciences from the Université de Montreal in 1999. She then completed a 5 year residency in Pediatrics. Marie-Claude is currently working on an interdisciplinary PhD from Dalhousie University on symptom assessment in the pediatric population. She loves puppets and stuffed animals and has a green friend, Dr. Bunsen Honeydew (from the Muppet Show), who makes appearances throughout the hospital.

Schoel Strang is the helpful and considerate Administrative Assistant for the palliative care service. Schoel keeps the rest of the team organized and is an invaluable member of the team. Schoel ensures information for health care professionals and families is available on each unit

with the IWK.

The IWK has an "in-born" nursery and mothers with high-risk pregnancies are sent from other centres within the Maritimes (Nova Scotia, New Brunswick, and PEI) for antenatal and post-partum care. This aspect of care, on occasion, involves antenatal consultation by the Pediatric Palliative Care team.

The large geographic area covered requires some creative outreach including telehealth consultations with clinicians in the child's distant community, a lot of time on the telephone, and being a resource to those providing care closer to or within the child's home. For specific patients; training sessions have been done at the IWK and within the child's community including the use of videos tailored for the individual child's care.

The team is involved in several research projects, with the most recent project focusing on pain and dyspnea in individuals with a diagnosis of cystic fibrosis. Policy development initiatives that the service is currently leading in the health centre include updating the do not attempt resuscitation policy and the implementation of a bereavement follow-up policy. The bereavement follow-up policy includes training health care providers throughout the health care facility to provide a minimum standard of bereavement follow up. In the last while the service has also implemented

policies on care at the end-of-life, which include the death of a patient policy, autopsy policy, and the organ and tissue donation policy.

The IWK Palliative Care Service has a key role in educating current and future health care professionals. The team is active in educational workshops which are multidisciplinary in focus and are held locally, regionally, and further afield.

Contact Information for the IWK Pediatric Palliative Care Service:  
5850/5980 University Avenue  
PO Box 9700  
Halifax, Nova Scotia  
Tel. (902)470-7262  
Email:  
schoel.strang@iwk.nshealth.ca

**Since we would like to feature different programs from across Canada, please share information about your program, the people who work with your program and the things you are doing and have done! Just email your information to:**

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

## **CNPCC NATIONAL SURVEY**

**(continued from page 1)**

formal and informal programs, services and activities that are aimed at the care of children with life-limiting/life-threatening illness. Therefore, all activities, even those delivered within adult care programs to children are of interest to us. The findings will be collated and the information obtained will be used to guide the development of standards, education, and research to help us advocate for the needs of this special population. We hope to also have a contact list of individuals with whom we can both disseminate information but also will use to help inform the work we do to advance the field.

Your assistance in completing this survey is very important. Without your input we will not be able to accurately and adequately represent the needs of children with life-limiting/life-threatening illness and influence any advancements in this field. Please read the instructions at the top of the first page of the survey and once completed return to Greg Adams at CHPCA whose contact information is at the end of the survey.

The survey is attached to the newsletter email and is also available in English and French at <http://cnpcc.ca>.

## FELLOWSHIP IN PEDIATRIC PALLIATIVE CARE

We are seeking applicants interested in undertaking a two-year M.D. Fellowship in Pediatric Palliative Care. The Fellow will train in clinical pediatric palliative care, pediatric pain management, and general (adult) palliative care. The Fellow will also complete a Master's degree in an appropriate field related to research or education. Funded by the Canadian Institutes for Health Research, the goal is to develop capacity in the field of PPC; it is expected that the Fellow will prepare for a career in PPC with specific interest in one or more of the following areas: research, education, program development. Training will take place at Canuck Place Children's Hospice, British Columbia's Children's Hospital, British Columbia's Women's Hospital, and the University of British Columbia. There will be opportunity to undertake training at other programs in Canada and the United States. Canuck Place Children's Hospice is North America's first free-standing children's hospice, and provides services to over 300 children and families. British Columbia's Children's and Women's Hospitals are the provincial tertiary care services for pediatrics and neonatology. Fellows must be eligible for an educational medical license in British Columbia.

Direct enquires to Dr. H. Siden,  
Canuck Place Children's Hospice  
1690 Matthews Avenue  
Vancouver, BC V6J 2T2.  
[www.canuckplace.org](http://www.canuckplace.org)

## PEDIATRIC PALLIATIVE CARE PHYSICIAN

**DESCRIPTION:** The Department of Pediatrics at Dalhousie University and the IWK Health Centre located in the wonderful harbour city of Halifax, Nova Scotia, is seeking a physician at the Assistant/Associate/Full Professor level. The successful candidate would be welcomed as the second physician for the pediatric palliative care team, which includes a pediatrician, Clinical Nurse Specialist, Bereavement Coordinator, and Administrative Assistant.

Training in Pediatric Pain/Palliative Medicine is a requirement with a demonstrable commitment to this focus of care. Preference will be given to applicants with clinical and research experience in pediatric palliative medicine. Responsibilities include the provision of pain and symptom management as well as supporting clinicians who care for children (both inpatient and outpatient) throughout the Maritime Provinces. Demonstrated interest in clinical research relevant to pediatric palliative care is an asset. Teaching opportunities abound within Dalhousie University, the IWK Health Centre, and more broadly throughout the urban and rural communities where care is collaboratively shared.

**CONTACT:** Please send curriculum vitae and letter of interest by June 30, 2005 to: Dr. Gerri Frager Medical Director Pediatric Palliative Care  
IWK Health Centre, 5850 University Ave. PO Box 9700  
Halifax, Nova Scotia, Canada B3K 6R8

If work in a collegial and truly satisfying environment, in a spectacular setting with abundant beaches, lakes and woodlands for the nature enthusiast balanced by excellent and diverse cultural venues, has appeal, then please contact [gerri.frager@iwk.nshealth.ca](mailto:gerri.frager@iwk.nshealth.ca)

Dalhousie University is an Employment Equity/Affirmative Action employer. The University encourages applications from qualified Aboriginal peoples, persons with a disability, racially visible persons and women. All qualified candidates are encouraged to apply; however, Canadian citizens and permanent residents will be given priority.

**Suggestions or  
submissions for the  
newsletter are  
welcome!**

**Email your ideas to:**

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

Newsletter Editor:  
Simone Stenekes