

CHILDREN'S ONCOLOGY GROUP (COG) & INTERNATIONAL SOCIETY OF PEDIATRIC ONCOLOGY (SIOP)



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Children's Oncology Group (COG)

In 2000, two major pediatric clinical trials cooperative groups, the Children's Cancer Group (CCG) and the Pediatric Oncology Group (POG) along with the two pediatric disease specific groups, the National Wilms' Tumour Study Group (NWRSG) and the Intergroup Rhabdomyosarcoma Study Group (IRSG) merged and formed the Children's Oncology Group (COG). Within the COG, the Nursing Discipline Committee was established with a mission to set the standard of excellence for the nursing care of children and adolescents with cancer treated on COG clinical trials, and to transform pediatric oncology nursing practice by developing and conducting research within COG.

Prior to 2000 few nurses in the cooperative groups had a primary responsibility of generating independent research. In 2000 I participated in the 'State of the Science Summit for Pediatric Oncology Nursing Research' held in Bethesda, MD. This was a real opportunity to consider the clinical application of 'do-ability' within clinical trials, after critique and review of a

research program and identification for the potential for this research to be applied to Children's Oncology Group nursing discipline research. This summit provided the opportunity to strengthen the working relationship amongst nurse researchers, staff nurses, and advanced practice nurses in pediatric oncology through a shared responsibility for shaping the nursing scientific agenda and contributing to the overall scientific agenda of the COG. The current Nursing Research infrastructure is comprised of one or more doctoral-prepared nurses and an advanced practice nurse focused on COG priority areas. Over the years this structure has been maintained with current nursing research studies (ANUR0631 & ACNS0331), nursing research traineeships, liaison with the Young Investigator Committee and other ongoing interdisciplinary collaboration within the COG.

Late in 2000 I was invited to lead the Education subcommittee of the COG Nursing Steering Committee. For the past 10 years I have been supporting nursing education activities as chair or as a member of the planning committee of five very successful COG nursing workshops. The ultimate collaboration began in 2009 when COG partnered with APHON (Association of Pediatric Hematology Oncology Nurses) to convene the first joint COG/APHON nursing workshop. This was followed in the fall of 2010 with the first APHON annual conference that had a specific 'COG Track' of education sessions for nurses to choose from in order to learn more about the nursing implications of caring for children on complex protocol therapies. The Education subcommittee is responsible for coordination and support of clinical trials-related, as well as development of protocol-related, education and training for

nurses. As new technologies, agents and protocols emerge, the Nursing Education subcommittee is responsible for rapid dissemination of pertinent protocol information to nurses in COG institutions who share the responsibility of safe and effective administration and monitoring of therapies.

The Clinical Trials subcommittee for COG nursing is responsible for making nursing assignments to COG disease, scientific, and individual protocol committees in consultation with the disease committee Chair and the Nursing Chair. Currently 100 nurses hold assignments on 142 active committees (35 scientific or disease committees and 107 protocol committees).

The COG nursing discipline contributes essential functions to COG as nurses care for patients on protocol therapy, serve on protocol study committees, and educate patients, families and staff about protocol care – these are the functions that have and will continue to be the cornerstone of COG nursing. Each COG protocol has a scientific/multidisciplinary team, and I have had the opportunity to be the study committee nurse on two recent/current COG studies – AAML0531 and AALL0631. This allowed me to be the nursing voice and part of the development, implementation and evaluation of the treatment we use on a daily basis to care for our patients.

A major aim of the COG Nursing Discipline Committee is to provide most up-to-date information to nurses who care for children and young people on COG protocols. The COG website offers Nursing Education modules, information about Nursing Research activities, newsletters and collaborative communications. Nurses can access this

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website by becoming a COG member. The same information can be shared by the COG 'Responsible Nurse' (RI) at each institution – Kerri Clement is the current RI nurse at BC Children's Hospital.

The first ten years of COG have now passed and with a new COG Group Chair, Peter Adamson, and a new Nursing Chair, Wendy Landier, the next ten years are certain to be full of new and exciting opportunities. The opportunities that I have had over the past ten years, working closely and collaboratively with many special nursing colleagues from all across North America, have provided me with a strength and richness of experience which is an integral part of who I am both as a pediatric oncology nurse and, now, in my current role in senior leadership at BC Children's Hospital.

International Society of Pediatric Oncology (SIOP)

SIOP (www.siop.nl) was established in the 1960's and has grown from a few members interested in a small number

of tumor groups to now over 1400 active members from all over the world. Each year the Society hosts a scientific congress on all aspects of pediatric oncology. Besides the annual meetings, SIOP sponsors regional and continental meetings to promote the exchange of information and good practice in pediatric oncology around the world.

In 2005 Vancouver was the host city for the SIOP annual congress, and I was the nursing representative on the local organizing committee. The SIOP Nurses committee was formed in the early 1990's, led by a committed group of nurses in Europe with both strong nursing research and clinical backgrounds in pediatric oncology. The congress in Vancouver was extremely successful and was attended by over 220 international pediatric oncology nurses, alongside 1600 delegates attending the scientific meeting. Since that time I have had the opportunity for continued involvement with election to the SIOP Nurses committee and since 2008 I have been Chair of the SIOP Nurses committee. Each year

for the annual SIOP congress the nurses committee plans with the local organizing committee a program for pediatric oncology nurses that runs concurrently with the scientific program. We receive increasing numbers of nursing abstracts each year for oral and poster presentations. We also have a collaborative joint session with the physicians, psycho-oncology group and/or parents and survivors of childhood cancer. The work of SIOP in low and middle income countries has grown and developed over the years, with SIOP nurses supporting and learning from nurses working in developing countries. This Pediatric Oncology in Developing Countries (PODC) initiative has recently restructured with many active working groups including a PODC Nurses group.

This year the annual SIOP congress takes place in Auckland, New Zealand from October 26-30, with the focused theme of Adolescents and Young Adults with Cancer (www.siop2011.com). The local nurses are working with nurses from the Pacific nations and their Australasia contacts to develop an exciting nursing program.

...WHEN OPPORTUNITY KNOCKED, WERE YOU THERE?

~Patti Byron~

Life is often about being in the right place at the right time, but it is also about preparing yourself with your experiences and commitment and having strategies to be ready when those moments present themselves. My journey into pediatric oncology nursing was somewhat by chance in that when I was looking for my first nursing job I was offered a position in the pediatric oncology program at BC Children's Hospital. Since that day in 1987 I have never looked back. I have

been fortunate to witness changes in the protocols of pediatric cancer treatment that have made a significant difference to the outcomes for our patients and their chances for improved survival.

I had the opportunity to attend my first CCG (Children's Cancer Group) meeting in 1994 and learned there was an active nursing committee with a clinical practice workgroup, an education workgroup and a research workgroup. I was excited that I could participate in sharing ideas and challenges from

everyday clinical situations, and that there was an experienced group of nurses who were actively problem solving the issues of caring for children being treated on clinical trials protocols

I encourage each of you to look for opportunities and reach out when moments arise in your nursing career as you will be surprised by what you can do, and all there is available to utilize your skills and be a part of, in the world of pediatric oncology nursing.



Kerri Clement, RN, MN, CPON
Clinical Nurse Coordinator
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COG RI-Nursing BCCH

THE ROLE OF NURSING IN CLINICAL TRIALS THROUGH THE CHILDREN'S ONCOLOGY GROUP

Forty years ago childhood cancer was virtually an incurable disease. Today, through collaborative research of the Children's Oncology Group (COG) there is hope for cure with current overall success rates of 78%. The COG is a network of more than 230 hospitals, in the United States, Canada and other countries around the world, that conducts research through clinical trials

to find cures for nearly 13,500 children and adolescents diagnosed with cancer annually (CureSearch, 2010). Each year, around 100-150 children in British Columbia are diagnosed with cancer. British Columbia Children's Hospital (BCCH) is one of the COG hospitals that strive for the best possible treatment for our oncology patients through clinical trials.

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I became involved in COG through Patti Byron, my previous Program Manager at BCCH. For many years, Patti was actively involved in the COG Nursing Steering Committee. She truly motivated me to get more involved in COG. At my first COG meeting, I was impressed with the strong nursing representation at COG with over 1700 members. Striving to set the standard of excellence for the care of children with cancer treated on COG clinical trials, the nursing discipline direct their work in three main areas: clinical trials, education and research. The COG Nursing Steering Committee is instrumental in highlighting the importance of nursing within COG. They provide the opportunity to network, and are excellent resources on how to get involved on protocol design and analysis, patient/family education and research projects.

I was recently assigned my first COG clinical trial. I am currently the study nurse representative for a new Ewing Sarcoma trial that is early in its concept phase. I frequently liaise with the study's Principal Investigator (PI) who updates me on the protocol's development. To date, the protocol is in Scientific Council review. I am excited to participate in the next steps once the protocol moves onto further development.

The COG study nurse has an integral role and responsibility in all stages of the clinical trial development. All clinical trials/protocols at COG are assigned a nurse representative during all stages of development. We are responsible for providing nursing expertise in the areas of protocol development, implementation and evaluation. Each nurse must carefully edit each draft of the protocol as it is being developed and provide feedback to the PI/or study chair. It is essential that the nurse examines the protocol with their nursing lens. Consideration of the patient's central line access, IV compatibilities, and level of nursing care required to carry out these protocols are examined. Nurses are also instrumental at considering other variables that may affect the patient/family's quality of life such as symptom management, caregiver burden and increased hospital admissions needed to participate in the trial.

The study nurse also assists to develop and review Therapy Delivery Maps (TDMs) that are now embedded into each protocol. The nurse develops the Family Protocol Summary for the study that is later posted on the CureSearch website www.curesearch.org. If the protocol is complex, the study nurse may need to consider a protocol teaching tool such as a training module to facilitate learning. Nurses play a critical role in assisting with this

process. Creating a tool that nurses can utilize when using a protocol in clinical care may include a description of hourly administrations, preliminary lab work, prehydration and when to administer anti-emetics. The study nurse may include this in an appendix within the protocol.

When our patients are treated on clinical trials, we rely on nurses at every level to offer the very best care required to support both the child and family during their treatment. From the COG study nurse, to nurses everywhere across BC who care for our patients, it is imperative that nursing continue to have a voice in clinical trials. The advances in research through clinical trials will always benefit from a nursing viewpoint. Nurses everywhere can make a difference in the treatment for childhood cancer.

I am a Clinical Nurse Coordinator for the inpatient Oncology/BMT unit at British Columbia's Children's Hospital in Vancouver. I have worked in pediatric oncology for the past 13 years, both as a bedside nurse and front-line nurse leader. I received my Masters Degree in Nursing from the University of Toronto. I am currently the COG-RI nurse for BC Children's Hospital and continue to disseminate COG information to all nurses caring for children on COG clinical trials.

~Kerri Clement~

PRINCE GEORGE PEDIATRIC ONCOLOGY SERVICES

In Prince George, pediatric oncology services are provided in the University Hospital of Northern BC's (UHNBC) Pediatric Ambulatory Care Clinic which opened with the new inpatient Pediatric wing in November of 2006. We currently have two bright and child friendly treatment rooms where our patients receive their chemotherapy treatment. We service Northern Health pediatric patients who live in the northern half of the province from Quesnel to the Yukon/Alaska border.

Currently we have four pediatric nurses who are chemotherapy competent: Kristine Brownscombe, Tracy Barwise, Sheri MacDonald, and Darlene Fjellgaard. Kristine is our clinic nurse who coordinates the oncology services with assistance from Jennifer Begg, Pediatric Nurse Navigator. They ensure that the families and health care team are well coordinated and that our service offers full coverage

throughout the week. Tracy is our Clinical Nurse Educator and Sheri is our Clinical Practice Leader for Pediatrics. They act as resources and support the activities of our oncology services during the week. Darlene is one of our inpatient pediatric nurses who assist to bridge any gaps in our coverage. Kristine remains our contact with the nurse clinicians at BC Children's Hospital to ensure that we continue to provide coordinated seamless care to the children and families we serve. All nurses involved in the program currently attend the Provincial Pediatric Oncology/Hematology Network Steering Committee Meetings.

Dr. Simon Earl, Department Head of Pediatrics at UHNBC, is the medical director of oncology services. Both Dr. Earl and Dr. Kirsten Miller currently care for our oncology patients. All six of our pediatricians are responsible for providing care when these patients

present in our clinic.

Our clinical pharmacists, Julie Gagnon, Rob Watt, and Alicia Ridgewell, continue to play an important role in our chemotherapy service by ensuring that the roadmaps are correctly interpreted and followed in collaboration with the physicians and nurses. Our team also includes Sandra Wyatt, Child Life Specialist, and Kim Foster, Pediatric Physiotherapist, who help to provide a more comprehensive service for our patients. Michelle Norn provides all clerical support to our program.

In addition we now boast the UHNBC Maternal Child Family Place located on the Pediatric Wing where patients and their family members can stay while receiving treatment.

~Jennifer Begg, Nurse Navigator~

CAMP GOODTIMES



Kate Kelsey is the Clinical Coordinator for the Canadian Cancer Society Camp Goodtimes program. Kate has worked as an oncology nurse at BC Children's hospital since 2000 and as a classroom teacher since 2003. She is currently working on a graduate degree which focuses on the academic needs of children with a history of cancer.

Attending camp as a child is an excellent venue for children to develop quality friendships, skills, and positive physical, social and emotional maturity. Camps that support children with any kind of special need are extremely important for both the children and their families. Programs such as Camp Goodtimes, which supports children and their families affected by childhood cancer, who may have unique and often complex medical, cognitive, and social needs, strive to create an environment that is inclusive, fun, and safety-minded.

Given that the majority of children with medical needs have been away from their peers and social networks for extended periods of time due to illness, they often describe feeling disconnected from their peers. At camp however, they do not face the same challenges they typically would in their daily lives. They will find themselves in the company of peers who have a common understanding of what it is like to have a disability, chronic or life threatening illness, or be a sibling with their own particular emotional needs. All medical and emotional needs are approached in a manner that values discretion, empathy, and a normalizing experience for all campers.

Camp Goodtimes provides an opportunity for children and caregivers to challenge themselves in ways they may not have thought possible. With an intentional shift of focus away from illness or condition and towards creating a normalizing and inclusive environment, campers are better able to feel a sense of belonging, which often leads to improved confidence and autonomy.

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Activities are designed so that all levels of ability may be included in some way. Campers find success and independence when they are making friendship bracelets, swimming for the first time since they were diagnosed, climbing the high ropes with or without the use of all of their limbs or sight, and in just about every other activity at camp. It may be the case that some children are more sick or more profoundly affected by their condition than others but, with thoughtful activity design and staff training, it would be difficult to immediately identify these children.

In addition to focusing on inclusivity, improving quality of life, and creating a normalizing environment, Camp Goodtimes is aware of the medical and health concerns of each camper. Health care practitioners bring the expertise and professional standards of their field to provide a high level of care in an environment that is quite different from that of a hospital or clinic. The most notable difference between the two work environments may be found in the work attire and general attitude of the staff; hospitals tend not to encourage their employees to dress and act as "superheroes" while at work.

UPCOMING EVENTS

Community CME Courses

April 7, 2011

Hoodooos at Sun Rivers, Kamloops, BC

April 8, 2011

Coast Capri Hotel, Kelowna, BC

May 19, 2011

TBA, Prince George, BC

For information about any of the above CME courses, please contact Paulina Chen at 604-875-2345 ext 7435 or (ppchen@cw.bc.ca)

APHON/COG

September 8-10, 2011

Anaheim, California

www.aphon.org/meetings/conference

SIOP 2011

October 26-31, 2011

Auckland, New Zealand

www.siop2011.com

Please note, the conference focussing on Adolescent Oncology "Too Young, Too Old, Where Do I Fit In?" has been postponed to 2012. More info to come.

The Provincial Pediatric Oncology/Hematology Network

The Network is an interdisciplinary organization whose goal is to ensure appropriate diagnosis, management, follow-up, and end-of-life care for pediatric patients with malignancies and blood disorders. The Network supports community hospitals and practitioners, and develops partnerships with other health care facilities to enable seamless and integrated care for patients and families on treatment and off treatment. It will further develop and enhance the research programs of basic, translational, and clinical research to better childhood cancer control and improve outcomes for these patients and their families.

For More Information

To learn more about the Provincial Pediatric Oncology/Hematology Network, or to submit articles or stories to this newsletter, please contact:

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TEEN ADVENTURES

Tofino Adventure

May 16-20, 2011

4 day surfing, kite flying, whale watching and beach combing

Sailing Adventure

June 20-23, 2011

4 day sailing trip

Kayaking Adventure

July 8-11, 2011

4 day kayak adventure in Gulf Islands

Horseback Adventure

July 28-31, 2011

4 day horse back trip

Whitewater Rafting Adventure

August 28-31, 2011

4 day whitewater adventure

Cost per teen per activity is \$190. For more information about any of the above activities, please contact Dan Mornar at 604-875-2345 ext 6477 or dmornar@cw.bc.ca.