CHILDREN'S ONCOLOGY GROUP

Nursing Newsletter

COG Nursing Newsletter - December, 2012

Contents:

Courtesy of Cincinnati Children's Hospital Medical Center

Editorial Board

Editor: Kathy Ruccione (kruccione@chla.usc.edu)
Web designer: David Amodei

COG Nursing Mission

The mission of the COG Nursing Discipline is to set the standard of excellence for the care of children and adolescents with cancer treated on COG clinical trials and to transform the practice of nursing in pediatric oncology by developing and conducting research within the COG.

Opportunities for Involvement

Application for Nursing Discipline Involvement

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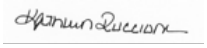
Editor's Note

With all the activity the holiday season brings, it is so nice to find moments to appreciate the gifts that don't come wrapped in shiny paper (or those lovely blue boxes with white ribbon from a certain favorite store). My Christmas cactus is in bloom and it makes me happy to see it so full of life and color as I close my front door in the mornings on the way to work. My colleague Scarlett Czarnecki posts a daily message of gratitude on her Facebook page and her infusions of positive perspective inspire me. Spending time with friends – those special people who share memories, stories, and laughter – feels particularly precious and irreplaceable to me at this time of the year. What are your treasured moments amidst the hubbub and, if we're honest, the sometimes sad times we experience as peds oncology nurses, in the holiday season?

We've prepared some gifts for you in this December issue of the COG Nursing Newsletter. You'll find a new feature: the Nursing COG BLOG. In it, your Nursing Discipline Subcommittee chairs write about the Fall 2012 COG meeting, giving you a snapshot of the nursing meetings from their point of view. This issue also includes a letter from your Nursing Chair, Wendy Landier, membership and committee appointment updates, and upcoming educational opportunities. And look for the announcement of the recent nursing elections, with a profile of Jennifer Wofford, your new Member-at-Large. As always, I look forward to hearing from you with any suggestions or feedback about the COG Nursing Newsletter so we can be sure that we're giving you a gift you enjoy and appreciate!

A couple more things I'm thankful for: all the wonderful people I've met because of COG, and our great good fortune of being able to do meaningful work together. In this holiday season, my wish for you is that you do find those small moments to appreciate the gifts awaiting you. You deserve them.



Kathy Ruccione, MPH, RN, CPON®, FAAN

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Nursing Newsletter

From the Nursing Discipline Chair

Dear COG Nursing Colleagues,

Nurses are change agents. I first remember hearing this concept many years ago, in my Introduction to Professional Nursing class. I also remember how it surprised me. At the time, my perception of nursing revolved around tending to the sick and wounded, helping to mend lives, to ease suffering. The role of "change agent" seemed far removed from what I had envisioned nursing to be. But over the years, I have come to appreciate the tremendously important role that nurses play in bringing about change – for our patients and for the health care system. Interestingly, the concepts of change and power are consistently linked in the literature.1 In Power and Innocence, the American existentialist Rollo May defined power as "the ability to cause or prevent change" (p. 99).2 By acting as change agents, nurses are harnessing change as a powerful tool with far-reaching possibilities.

Within COG, we have many examples of how nurses are bringing about important changes. This year, an excellent exemplar is the Evidence-Based Practice project led by Maki Okada, CPNP, FNP-BC, CPON®, under the guidance of Marilyn Hockenberry, PhD, RN, PNP-BC, FAAN, and Cheryl Rodgers, PhD, RN, CPNP, CPON®. Maki and her team at Children's Hospital Los Angeles took on the task of developing evidence-based recommendations for safe forms of exercise in mononephric childhood cancer survivors. Their conclusions? Evidence from current literature indicates that serious renal injuries are rare; when they do occur, they are most commonly related to automobile accidents, all-terrain vehicle accidents, and falls, rather than to sports participation. Renal injury in sports is rare (0.05-1.3%) and nephrectomy even rarer (0.008%). The benefits from physical activity and sports, including improved physical health (strength, stamina, decreased risk for metabolic syndrome) and improved quality of life, far outweigh the risks. Ultimately, patients and families must decide how to proceed after receiving evidence-based information. Maki presented the team's findings at the COG Fall Meeting in Atlanta and is in the process of submitting these findings to the Survivorship and Outcomes Committee, for potential inclusion in the COG Long-Term Follow-Up Guidelines and Health Links. It is not difficult to imagine the life-changing possibilities that these recommendations will hold for young mononephric cancer survivors. What a wonderful example of nurses as change agents!

The COG Nursing Leadership has also recently considered the power and possibility of change as we developed our Discipline's strategic plan for the next 5 years. This plan includes the following 5 key initiatives that address our Discipline's vision† and mission.‡

- Facilitate inclusion of nursing expertise across Group activities to support the conduct of research, with a focus on leadership development, succession planning, and mentorship of young investigators
- Develop clinical resources to facilitate protocol-related nursing care using evidence-based methodology
- Develop and disseminate instructional programs to update/increase nurses' knowledge regarding protocol-related care
- Develop and implement patient/family education across the cancer continuum; and assess the impact of this education on knowledge gained, resilience, and overall quality of life of patients and their families
- Describe the burden of illness-related distress (physiologic and emotional) experienced by children, adolescents, and young adults with cancer and their family caregivers, identify vulnerable sub-populations, and use this information to develop targeted interventions to improve resilience and overall well-being.

As the year draws to a close, many of you will be reflecting on your blessings and making plans for the upcoming year. I count among my most treasured blessings the incredible community that is COG Nursing – and I thank each of you for all that you do, day in and day out, for patients and families facing childhood cancer. As you make plans for the upcoming year, I would challenge you to reflect on how you are fulfilling the role of change agent in nursing. If you would like to join in any of our COG initiatives aimed at effecting change – I would love to hear from you.

Best wishes,

Wendy Landier, PhD, RN, CPNP, CPON®
Chair, Nursing Discipline
Children's Oncology Group
wlandier@coh.org

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1 Norton, S. F. & Grady, E. M. (1996). Change agent skills. In A. B. Hamric, J. A. Spross, and C. M. Hanson (Eds.) Advanced nursing practice: an integrative approach. Philadelphia: W. B. Saunders.
2 May, R. (1972). Power and Innocence. New York: W. W. Norton.
†COG Nursing - Vision: To protect, maintain, and improve the quality of life of young people during and after treatment for cancer.
‡COG Nursing - Mission: To set the standard of excellence for the 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 the COG.

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Thank You From the Nursing Discipline Chair

As this year draws to a close, we can all take pride in what we have accomplished together. I would like to extend my sincere thanks to the following individuals who have made significant contributions to the COG Nursing Discipline over the past year:

Nursing Steering Committee
- Marcia Leonard (Vice Chair)
- Joy Bartholomew
- Maureen Haugen
- Casey Hooke
- Kathy Kelly
- Carol Kotsubo
- Peggy Kulm
- Katy Murphy
- Kathy Ruccione
- Jennifer Wofford

Courtesy of Miller Children's Hospital

ANUR1131 Principal Investigators
- Joan Haase
- Sheri Robb

Evidence-Based Practice Task Force
- Marilyn Hockenberry (Chair)
- Joy Bartholomew
- Susie Burke
- Casey Hooke
- Melissa Hudson
- Kathy Kelly
- Cheryl Rodgers

Speakers – COG Track at APHON
- Shari Feinberg
- Maureen Haugen
- Amy Kaplan
- Marcia Leonard
- Jenny Madden
- Amy Newman
- Mary Lynn Rae
- Teresa Rushing
- Rita Secola
- Kristin Stegenga
- Liann Stogsdill
- Ann Stratton
- Christine Yun

Planning Committee/Slide Module Review – COG Track at APHON
- Maureen Haugen (Chair)
- Carol Kotsubo

- Meredith Lal
- Marcia Leonard
- Jenny Madden
- Kathy Ruccione
- Karla Wilson
- Eric Gasber

Presenters - COG Fall Meeting
- Kathy Ruccione
- Marcia Leonard
- Maureen Haugen
- Denise Mills
- Steven Joffe
- Kathy Kelly
- Lillian Sung
- Maki Okada
- Christine Yun
- Sue Zepanec
- Joy Bartholomew
- Casey Hooke

Courtesy of Raymond Blank Children's Hospital

Authors – APHON Counts COG Feature of the Quarter Columns
- Kathryn Murphy, "Making the Most of the COG Family Handbook for Children with Cancer"
- Stacey Senn, "Protocol Safety in the New Children's Oncology Group High-Risk ALL Trial"
- Ann Stratton, "What is Old is New Again: Acupressure for Pediatric Oncology Patients"
- Lona Roll, "Clinical Nurses and Behavioral Nursing Research: Lessons from the SMART Study"

Nursing Nominating Committee
- Jenny Madder (Chair)
- Kerri Clement
- Connie Dinning
- Peggy Kulm
- Jill Lunsford Lee

Candidates – COG Nursing Fall Election
- Cindy Cochran
- Beth Fisher
- Meghan Markley
- Shirley Perry
- Ann Stratton
- Jennifer Wofford

CEU Coordinator
- Kelly Laschinger

Membership Committee Representative
- Lona Roll

Young Investigator Committee Liaison
- Celeste Phillips-Salimi

Representative to the Osteosarcoma Biology Subcommittee Chicago Meeting
- Amy Newman

APHON Collaborations
- Melody Watral

- Kathleen Adlard
- Dave Bergeson
- Nicole Wallace

Return of Results Initiative
- Kathy Ruccione
- Casey Hooke
- Conrad Fernandez

COG Public Website
- Dave Amodei
- Maria Hendricks
- Katy Murphy
- Marcia Leonard

Family Handbook (Editing and Translating)
- Kathryn Murphy (Editor)
- Lanipua Yeh-Nayre
- Yolanda Millan
- Dominique Lafrenière
- Linda Hershon
- Patrick Cossette

Courtesy of Cincinnati Children's Hospital Medical Center

Nursing Discipline Strategic Planning
- Joan Haase
- Pam Hinds
- Marilyn Hockenberry
- Ki Moore

Family Protocol Summary Development
- Marcia Leonard
- Kathy Ruccione

Nursing Discipline Traineeships
- Kathy Kelly
- Casey Hooke
- Kristin Stegenga
- Cheryl Rodgers
- Catherine Fiona Macpherson
- Jessica Anne Ward
- Brandy Winkle

COG Leadership/Administration
- Peter Adamson
- Maria Hendricks
- Liz O'Connor

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COG Nursing Election Results

The COG Nurse Nominating Committee is pleased to announce the results of our recent election:

The new Nursing Member-at- Large is **Jennifer Wofford**, APRN, PNP-BC (left). Please see Jennifer featured in this issue's "Profiles in COG Nursing."

The two new members of the Nurse Nominating Committee are **Ann Stratton**, MSN, CNP (center) and **Cindy Cochran**, MSN, RN, CPNP (right).

Jennifer Wofford, APRN, PNP-BC

Ann Stratton, MSN, CNP

Cindy Cochran, MSN, RN, CPNP

CONGRATULATIONS!

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Profiles in COG Nursing:

Jennifer Wofford, APRN, PNP-BC

Jennifer Wofford, your newly elected Member-at-Large (MAL) is a hematology-oncology nurse practitioner at St. Louis Children's Hospital/Washington University. In COG, her area of special interest is Phase I studies, and she serves as the nursing representative on a Hodgkin disease protocol. At home in St. Louis, a favorite pastime and stress buster is cooking for her husband and son. In both worlds, Jennifer exemplifies chef Jacques Pepin's philosophy: "Great cooking favors the prepared hands." We asked Jennifer to share her thoughts as she embarks on her role as our newest MAL.

Could you tell us something about your background? Where did you complete your nursing education? I have been a nurse since 2003. I graduated from St. Louis University with my BSN and went on to work at Cardinal Glennon Children's Hospital on the Hematology Oncology Floor for about 4 years. It was at that point that I decided my calling was to be a nurse practitioner. Although I wasn't quite sure what I wanted to do with my PNP when I finished, I knew that's what I wanted to be. I went to the University of Missouri in St. Louis and continued to work at Cardinal Glennon during this time, but decided to mix things up a little bit and moved to the ER. I really missed my oncology patients, but I loved the ER and have never regretted my time there. I got some of the best experience of my life in that ER. Once I was done with my degree and passed my boards, an opening came up for a hematology/oncology PNP position at St. Louis Children's Hospital. I still wasn't completely sure what I wanted to do yet, but decided to go on the interview anyway. As soon as I walked into the interview I knew I had found my place! I have been here now for 3 years.

What factors influenced your decision to become a nurse practitioner?

I loved being a clinical nurse, but I always wanted to do something "more." I have several uncles who are doctors and they tried numerous times to convince me to go to medical school. I contemplated this briefly, but knew that I love being a nurse. I felt that becoming a doctor would shift my focus away from what I most love doing. I love providing personalized patient care. I love that my job includes going into a room and being able to simply hold a patient while a parent steps out of the room. So being a nurse practitioner seemed a perfect next step. As a PNP, I could take on a role with more medical responsibility without leaving nursing. I enjoy being a teacher to families and my fellow staff members and as a nurse there are so many different roles that I can step in and out of on a daily basis. By becoming a nurse practitioner I feel that I have opened myself up to even more opportunities and areas of growth.

How long have you been in pediatric oncology? What brought you to this specialty? What keeps you in it?

It never fails. Any time I tell anyone what I do – if they're not in the same field – I always get the same response. The person usually sighs, frowns, and asks me how I can do what I do. Clearly these people have not been around many pediatric cancer patients. I immediately tell them that, contrary to popular belief, not all children with cancer do poorly and that in fact, the opposite is true. This is one of the most hopeful and joyful groups of patients that I have ever had the honor of caring for. I love taking caring of the same children on a regular basis and getting to see them get better and do well, reach milestones and overcome the impossible at times. I like that with this particular field of nursing I get to work with entire families, do teaching and serve an active role in the child's frequent care. Not to say that there aren't times when things are hard or difficult, but I think that this applies to all areas of nursing. There is something about these children that is so hopeful, and I am reminded of this every day at work – it's funny how bald heads begin to look normal! For me, the good things often, if not always, outweigh and outnumber the difficult situations and days.

Your primary interest is in Phase I clinical trials. Knowing how challenging it can be to take care of children whose clinical situation makes them eligible for Phase I trials, what helps you keep your personal balance?

Cure rates for childhood cancer are at an all time high, and hopefully this number will only keep going up! It is always sad and difficult when there are children for whom treatment just does not work; however, I remind myself that every treatment we now have started as a Phase I, and that even though a Phase 1 option may not offer a cure today, that doesn't mean that it won't provide a cure to someone in the future. My experience with these patients and families is that often they have a realization of their situation and though they are not necessarily looking for a miracle, they have not given up hope. Seeing others have hope in what may seem like hopeless situations reminds me just how strong these families and patients are. Again I am reminded of how special this patient population is and how honored I am to be involved with their care.

What kinds of experiences in COG or elsewhere sparked your interest in running for the MAL position?

My interest in COG and the MAL position stems from the fact that I love my job. I get excited about what I do and want to share this with others. Treatment success for childhood cancer is higher than it has ever been and it is exciting to be able to be a part of it and know that you are helping deliver life saving treatment. Nurses are on the front lines, administering the medications and the hands-on nursing care, and implementing the protocols. But if they don't understand clinical trials and their importance, how can we expect them to provide expert protocol-based care? At my institute I strive to support our nurses and provide them with the resources to help be the best nurses they can be in regard to understanding protocols and being able to answer patients' and families' questions. Helping nurses realize how vital their role is in executing excellent nursing care is very important to me. Pediatric oncology nurses are amazing nurses, but I think that many nurses just don't understand the role of the COG and how they can get more involved. As a MAL, I feel that I will be able to help them learn about COG and support them in whatever ways I can so they can get involved. I feel that I have always been supported by those around me and I want to be able to pay that forward.

What do you hope to accomplish in your term of office?

Carol Kotsubo did an amazing job in her term as MAL. I will try my best to follow in her footsteps and pick up where she left off. Carol and I are working together for a smooth transition. I recognize that communication among nursing members is going to continue to be an area for improvement and I am hoping to be able to use the technology we have available for greater communication, and that we can present more opportunities for nursing involvement through educational offerings. As an APHON member, continuing to foster a strong relationship with APHON is also a priority for me. The MAL role includes being responsible for the COG column in APHON counts. This is something brand new to me and I am looking forward to the challenge. I look forward to learning more and more about my MAL role and bringing as much as I possibly can to it. Most of all, I want to be able to be a resource to other nurses and to welcome them to participating in COG.

Anything else you'd like to share about your experiences in COG Nursing, COG or peds oncology? Or life in general?

I love trying new things and I welcome new challenges. One of my favorite things to do is travel, even though I seldom get to the chance! I have been married to my wonderful husband for 7 years and we have a beautiful 2 year old little boy named Benjamin. I love cooking and it is the way I relieve stress. And I love spending time with my son and family.

What does a Member-at-Large do?

- Speaks for the general nursing membership in COG and provides orientation and leadership to new members of the nursing discipline
- Serves as a conduit of information and ideas from membership to the nursing leadership
- Liaises with and collaborates with APHON and other professional organizations, such as ONS and SIOP
- Leads the development, implementation, and evaluation of innovative teaching strategies and tools for patients and families related to clinical trials (such as the Family Handbook)
- Reviews project proposals from the Nursing Subcommittees for appropriateness of fit with the mission of the COG Nursing Discipline
- Collaborates with other disciplines to move the Nursing Discipline and COG strategic plan forward

You can reach Jennifer by email at Wofford_J@kids.wustl.edu

CHILDREN'S ONCOLOGY GROUP

Nursing Newsletter

Children's Oncology Group Nursing Discipline

Call for Evidence-Based Practice Proposals

- Are you interested in using evidence to identify optimal nursing practices?
- Are you interested in applying the evidence-based process to pediatric oncology clinical trials nursing?
- If so, please consider submitting a COG Nursing Evidence-Based Practice (EBP) Proposal.

The COG Nursing Discipline is committed to promoting best nursing practices for children and adolescents receiving protocol-based care, and is pleased to announce its second call for evidence-based practice proposals.

Proposals should address one of the following topic areas:

1. Standardization of nursing practices related to chemotherapy administration
2. Effective delivery of patient/family education
3. Standardizing information for patient/families regarding risk of infertility or fertility preservation options

Please see the next page for specific suggestions within each of these topic areas.

The deadline for proposal submission is Friday, January 18, 2013

APPLICATION PROCESS:

1. Assemble a Nursing Expert Team, which typically comprises 3-4 individuals with 1-2 team leaders. Team leaders must be COG nursing members.
2. Identify a problem statement.
3. Complete the COG Nursing Discipline Project Proposal Form for Evidence-Based Clinical Resource Materials (available on the COG Member Website – see link below under "Resources").
4. Submit the completed Project Proposal Form on or before Friday, January 18, 2013 to Dr. Cheryl Rodgers (cherylrodgers85@gmail.com).

Resources:

1. Materials to support the Evidence-Based Practice process are available on the COG Nursing Discipline Website, as listed below. You can access these materials via this link: https://members.childrensoncologygroup.org/disc/nursing/default.asp
- COG Nursing Evidence-Based Practice Procedure Manual
- Project Proposal Form for Evidence-Based Clinical Resource Materials
- SOP-Clinical Resource Material Development
- Guidance for Leaders – Clinical Resource Material Development
- Multimedia file (PowerPoint with audio) of Dr. Marilyn Hockenberry's presentation, "Strengthening Nursing Practice with Evidence," from the 2011 COG Fall Meeting in Atlanta

2. The selected teams will receive instructional sessions regarding the EBP process from Dr. Marilyn Hockenberry, and ongoing mentoring from Cheryl Rodgers and/or Janice Withycombe.
3. The selected teams will be provided with all literature that is necessary for project completion and not available through their institution(s) without cost to the team.
4. The team leaders will attend a 2-day translation science workshop, led by Dr. Marilyn Hockenberry, and held at the Oncology Nursing Center of Excellence at Duke University in July 2013. Alex's Lemonade Stand has generously provided a grant to cover expenses for the workshop and travel (maximum $1000 in travel costs).

Expectations:

- The selected project will be announced by February 22, 2013.
- A rigorous, evidence-based approach will be used to complete the EBP project.
- Team leaders will participate in scheduled conference calls with their mentors throughout the process
- Team leaders will attend a 2-day workshop sponsored by Alex's Lemonade Stand, which will be held at the Oncology Nursing Center of Excellence at Duke University in Durham, North Carolina in July 2013.

- The selected project will be completed by August 30, 2013 and presented at the Fall 2013 COG meeting.

2013 Topics for COG Nursing Discipline EBP Proposals

1. STANDARDIZATION OF NURSING PRACTICES RELATED TO CHEMOTHERAPY ADMINISTRATION

Rationale: Variations in nursing practice related to chemotherapy administration can result in unintended discrepancies in protocol-directed therapy. Best practices should be identified and standardized to reduce variation in practice and enhance care delivery.

Examples: Any proposals focusing on questions surrounding nursing practices related to chemotherapy administration will be considered. Examples include: (1) Differences in practice related to blood sampling methods for methotrexate levels (e.g., central venous vs peripheral venous vs fingerstick); (2) Variations in delivery of hydration pre- and post-chemotherapy (e.g., for cyclophosphamide, cisplatin, ifosfamide); (3) Inconsistencies in methods used to measure urine specific gravity; (4) Preparation and administration of oral medications used in protocol-specific care to children unable to swallow pills; (5) Best practices for assessing and/or optimizing oral chemotherapy compliance; (6) Patient positioning after intrathecal chemotherapy administration; (7) Assessment and documentation of chemotherapy administered by home health nurses (8) Vital sign monitoring during specific chemotherapy infusion; (9) Other

2. EFFECTIVE DELIVERY OF PATIENT/FAMILY EDUCATION

Rationale: Best practices in delivery of patient/family education in pediatric oncology should be identified in order to facilitate acquisition of patient/family knowledge regarding self-care and reduce knowledge deficits that can potentially affect protocol-directed therapy.

Examples: Any proposals focusing on questions surrounding patient/family education will be considered. Examples include (1) Optimal timing/content of patient/family education for newly diagnosed families; (2) Optimal methods for delivery of patient/family education; (3) Other

3. STANDARDIZING INFORMATION PROVIDED TO PATIENTS/FAMILIES REGARDING FERTILITY PRESERVATION OPTIONS PRIOR TO THERAPY INITIATION

Rationale: Information offered to patients/families regarding risk of infertility and fertility preservation options could be standardized based on planned protocol therapy, enhancing opportunities for patients and families to access fertility preservation services when appropriate

Examples: Any proposals focusing on questions surrounding information provided to patients/families regarding fertility preservation will be considered; multidisciplinary approaches are encouraged. Examples include: (1) Identification of currently viable options for fertility preservation appropriate to patient age, gender, and developmental status; (2) Review of evidence to determine fertility-associated risks related to selected protocol-directed therapies; (3) Other

Have Questions or Need Advice? Please Contact:

Cheryl Rodgers	**Joy Bartholomew**	**Marcia Leonard**
cherylrodgers85@gmail.com	joyb@cmh.edu	marcia@umich.edu

CHILDREN'S ONCOLOGY GROUP

Nursing Newsletter

Nursing COG BLOG: From the Fall 2012 COG Meeting

Nurses at the table

The value of the nurse on a protocol is really obvious to the other study team members these days – more so than ever before. I think this increased recognition and appreciation may be somewhat due to the complexity of the care it takes to deliver therapy to kids on these mega challenging studies. Nursing input is huge as we are the "make it happen" link between protocol and patient. We are the experts and so our face-to-face time at the COG disease committee table is hugely important. The physician PI's and other study professionals need to know us by name and face. We need to be experts in the disease we are representing and not just filling a role to jump start our COG nursing activity. That's why COG Nursing is gathering a group of nurse experts for every disease. Since disease committee activity is always changing, such a core group will need to be dynamic as well. The disease committee nurses (DCN's) know the nurses currently on studies and can strengthen our representation at the table. This is a very exciting time for nursing as we put our best foot forward in serving on all disease committees. There was a lot of discussion at the DCN and protocol nurse break-out session about who would like to take on such a core role.

Slides and minutes from all of the COG Nursing Meetings held in Atlanta are available at this link: https://members.childrensoncologygroup.org/Disc/nursing/Meetings.asp

There was also an opportunity to fill out an application for nursing involvement for those who are already experts in specific disease areas, but haven't been on a study yet. If you haven't filled out a form yet, you can find it on the COG nursing website (https://members.childrensoncologygroup.org/_files/disc/nursing/ApplicationforNursingDisciplineInvolvement.doc). So go for it! Nursing experts are just being identified now so if you missed the fall meeting it's not too late. I know our DCN's will see to it that nursing is well represented at the disease committee table.

Joy Bartholomew, FNP-BC
Co-Chair, Nursing Clinical Trials Subcommittee

A new twist on COG Nursing research

At our meeting in Atlanta, we heard from our two nursing trainees who just completed their two-year traineeship: Dr. Fiona Macpherson and Dr. Kristin Stegenga. Both did secondary data analyses. This means that they dove into data that already existed in a completed study, but the data set they used wasn't part of the primary aim of the study. The beauty of secondary data analysis is that you don't have to spend all the time and resources collecting the data – it's ready to go – and you learn a lot about research working with the statistician to analyze the data set. Fiona presented results of her exploration of the relationship between self-reported fatigue and self-reported physical activity in survivors of Hodgkin disease who were treated as adolescents/young adults (AYA) on AHOD0031. Kristin described her examination of AYAs' symptom experience (fatigue, pain, depressed mood, anxiety) during stem cell transplant (SCT). The results of their traineeship work are posted on the nursing COG website and they are both working on manuscripts to publish their results. After hearing form Fiona and Kristin, our new trainees, Jessica Anne Ward and Brandy Winkle, presented what they will be doing over the next two years. It will be fun to track their progress as they report at each COG meeting.

This year we tried a little different angle for the nursing research scholar meeting. At the COG meetings, there is so much packed into the sessions, we often don't have time to learn what other disciplines are doing or to share our work with them. So, we collaborated with the Behavioral Sciences Committee in a joint session. Two nursing scholars shared their programs of research. Dr. Joan Haase discussed the AYA music video intervention study

Themes across all the presentations:

- *Each study you do helps you learn more about what is effective and what isn't, and guides you to your next study,*
- *Sometimes a great idea doesn't pan out, but you keep going*
- *Research is both fun and hard work*

that she and her team have conducted within COG. Dr. Tina Baggott shared her research program (from outside of COG) that has focused on symptoms and symptom management using technology, most recently an iPhone. From the Behavioral Sciences Committee, Dr. O.J. Sahler presented a summary of her research using a problem solving skills intervention with mothers of children with cancer, and Dr. Kristi Hardy presented her work with COG using CogState, a computer-based brief neuropsychological assessment instrument. I was struck by the intelligence, persistence, and vision of each scholar. I also wanted to play match-maker among researchers whose work I am familiar with…I was thinking, I wonder if person A knows about person B, wouldn't they be a great pair to collaborate together! It would be wonderful if we had more forums for learning from each other. So much to learn and so little time at these meetings!

Casey Hooke, PhD, RN
Co-Chair, Nursing Research Subcommittee

Good discussion about education

The COG Nursing Education Subcommittee Annual Meeting was held on 9/14/12 at the end of 2 days of nursing meetings filled with lots of information, new ideas and camaraderie with nurses from all across North America. After an introduction of the committee and its charge we began with the priorities and plans, based on the results of the 2010 Needs Assessment Survey. Our surveyed members wanted the COG Track at APHON to continue, as well as the postings of these presentations in a multimedia form on the COG member website. They also wanted us to explore being able to provide CEUs to the on-line multimedia postings and podcast COG nursing meetings for those unable to attend, add an "Education Column" to the COG Nursing Newsletter (is this a good start?!?) and expand patient/family education. I explained to the audience a past project, "The C10403 Education Module for Adult Healthcare Providers," which has since been completed, highlighting how the Clinical Trials and the Education Subcommittees work together. Then we discussed the need for reviewers to update the 2007 "Cytogenetics for Nurses" education module. If anyone is interested in helping with this, an easy way to become involved in COG Nursing, please contact Joy Bartholomew at joyb@cmh.edu.

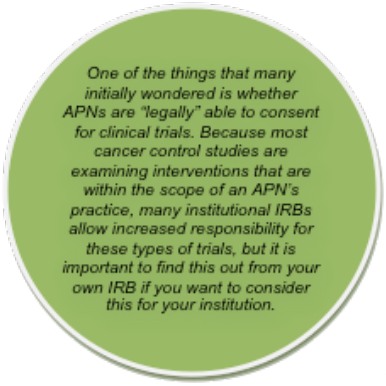
Ideas for the COG Track at APHON 2013 were tossed around. Lots of good ideas for presentations were collected! I am always looking for education topics having to do with COG clinical trials: new drugs, difficult protocols, challenging diseases. If you have any ideas or suggestions, please email me at mhaugen@luriechildrens.org at any time!

Current patient/family education media developed by COG Nursing were presented. We had a good time showcasing the COG Public Website and the Family Handbook in all 3 languages. We ended the meeting by brainstorming about the entire future of COG nursing education!

Maureen Haugen, RN, MS, CPNP, CPON
Chair, Nursing Education Subcommittee

Can APNs tackle Cancer Control studies?

The Nursing Discipline had a really fun joint session with the Cancer Control Committee, stemming from previous discussions about how to increase enrollment on cancer control and supportive care trials. We knew that these studies needed an institutional champion to facilitate enrollment. We also knew that there were some COG institutions where advanced practice nurses (APNs) had essentially assumed responsibility for enrolling patients on cancer control trials. So we planned this educational session to spread the word in hopes of stimulating APNs to go back to their institutions and begin similar efforts. We asked APNs from three institutions to discuss their experiences. Marcia Leonard from the University of Michigan in Ann Arbor, Maureen Haugen from Lurie Children's Hospital of Chicago and Denise Mills from Sick Kids in Toronto, Canada all talked about their how they set up or were setting up their programs.
Common practices from across all three institutions included setting up a team of individuals to commit to this new role and regular meetings to discuss enrollment and troubleshoot how to improve enrollment. The biggest obstacle that most places encountered was getting the cancer control studies opened at their institution. Because their CRA time is limited, therapeutic trials



always took priority.

We invited Steve Joffe, MD, the Chair of the Bioethics Committee, to discuss regulatory and practical issues related to obtaining parental permission and child assent for cancer control and supportive care clinical trials. He gave a great talk that focused on the nuts and bolts of conducting an effective consent conference. One thing he emphasized is that informed consent is a noun, not a verb. In fact, you don't "consent" people – people with the capacity to do so, make a decision for themselves about participating in a research study. In pediatrics, informed consent is a dual process of parental permission and child assent. He recommended a stepwise approach to discussing research participation with families. First make sure they understand the disease and clinical status and the current established treatment before you help them understand the clinical trial.

After the talks, we divided into three groups to role play different "real life" consent challenges. The discussion was lively and engaging. Several of the participants really got into their roles. We almost needed a family therapist for the scenario about the teen not wanting to participate in the adherence study when the parent really wanted them to do so! Based on the discussion after the session, people really appreciated the content and especially enjoyed the active learning. If you want to learn more about the session, you can find the slides on the COG Nursing Discipline website at the following link: https://members.childrensoncologygroup.org/_files/meetings/Atlanta2012/Nursing-CCLSymposiumAPN-LedProgramsFall2012.pdf

If you have questions about setting up a similar program at your institution, please contact one of the presenters:

mhaugen@luriechildrens.org, marcia@med.umich.edu, or denise.mills@sickkids.ca.

Kathy Kelly, PhD, RN
Co-Chair, Nursing Research Subcommittee

CHILDREN'S ONCOLOGY GROUP

Nursing Newsletter

Protocol News: Ch14.18 Antibody Update

In March 2009, the interim monitoring of the Data Safely Monitoring Board noted that the experimental arm (regimen B) of the COG study, ANBL0032 (Phase III Randomized Study of Chimeric Antibody 14.18 (ch14.18) in High Risk Neuroblastoma following Myeloablative Therapy and Autologous Stem Cell Rescue) demonstrated superior efficacy [2 year EFS of 66±5% for those children receiving the experimental (immunotherapy) arm compared to 46±5% for those receiving CRA alone]. These findings prompted the closure of the standard arm and all eligible patents were then nonrandomly assigned to the ch14.18 with cytokines arm.

For the ch14.18 immunotherapy to be available to all children with high risk neuroblastoma, the antibody must undergo several steps to transition it from an NCI- prepared study drug to one that is commercially available. United Therapeutics (UTC) is a biotechnology company that focuses on the development and commercialization of unique products to meet the needs of rare patient populations, such as children with high risk neuroblastoma.

Courtesy of University of Mississippi Medical Center

Several COG institutions will be participating in the effort to make ch14.18 commercially available through a comparative product study, A Comparative Pharmacokinetic and Safety Study of Chimeric Monoclonal Antibody ch14.18 with Granulocyte-Macrophage Colony-Stimulating Factor (GM-CSF), Interleukin-2 (IL-2) and Isotretinoin in High Risk Neuroblastoma Patients Following Myeloablative Therapy.

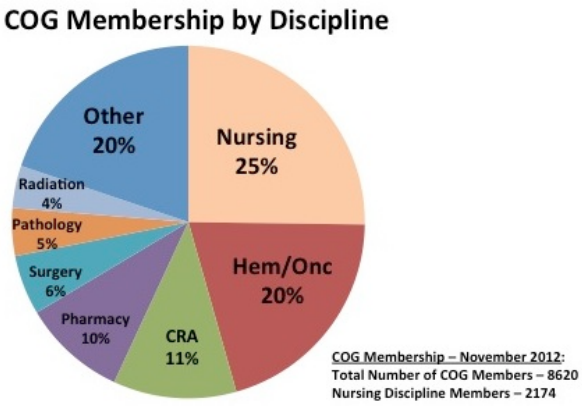
The basis of this comparative pharmacokinetic study is consistent with the ANBL0032 study in regard to timing and eligibility. However, in order to accurately compare the two products it must be designed as a two-sequence, cross-over study. This means that all children will receive both the NCI- and the UTC-prepared drug. Due to variances in the mathematical calculation of concentrations, the doses are equivalent though different. Multiple safety and lab assessments will be done. These assessments as well as the antibody will be provided at no cost to the patient. Ideally, less than 30 patients will be necessary to acquire the data to take the next step toward making this antibody commercially available to all children with high risk neuroblastoma.

Joy Bartholomew, FNP-BC
Co-Chair, Nursing Clinical Trials Subcommittee<,p>

CHILDREN'S ONCOLOGY GROUP

Nursing Newsletter

Welcome to New COG Nurse Members



COG Membership – November 2012:
Total Number of COG Members – 8620
Nursing Discipline Members – 2174

Welcome to 106 New* and Upgraded COG Nurse Members! **(**since the August Nursing Newsletter*)**	
New Member	**Institution**
Kimberly Duback	Advocate Hope Children's Hospital
Lynn Donini	All Children's Hospital
Elizabeth Eisenman	
Rebecca Flory	
Lindsay Jones	
Jennifer Pardee	
Terry Armstrong	Baylor College of Medicine
Carlie Kinnie	British Columbia Children's Hospital
Robert Parker	Cardinal Glennon Children's Medical Center
Kelly Smith	
Leslie Lingafeldt	Carolinas Medical Center/Levine Cancer Institute
Patricia Schumacher	
Catherine Jordan	Children's Healthcare of Atlanta - Egleston
Elizabeth Record	
Ashley Smith	
Rita Wilson	
Meghan Reid	Children's Hospital, London Health Sciences Centre
Amanda Smith	Children's Hospital and Medical Center of Omaha
Jennifer Flynn	Children's Hospital Colorado
Urvi Sanghvi	
Phylise Seldin	
Courtney Culbertson	Children's Hospital Medical Center of Akron
Jonathan Matters	Children's Hospitals and Clinics of Minnesota - Minneapolis
Emily Cowden	Children's Mercy Hospitals and Clinics
Lisa Wright	
Jennifer Mangino	Cincinnati Children's Hospital Medical Center
Andrea Pyle	
Ashleigh Haggard	Cook Children's Medical Center
Jennifer Russell	
Patricia Perez	Covenant Children's Hospital
Alyssa Mandell	Dana-Farber Cancer Institute
Veronica Maunz	
Cynthia Henao	Driscoll Children's Hospital
Ambie Hayes-Crosby	Eastern Maine Medical Center

Christina Amparado	Hospital for Sick Children
Lindsay Jibb	
Jennifer Stinson	
Duane Herbel	Johns Hopkins University
Vida Tubera	Kaiser Permanente-Oakland
Minhhang Vu	
Claudia Meredith	Kosair Children's Hospital
Jessica Cupples	Lehigh Valley Hospital - Muhlenberg
Agnes Natonton	Loyola University Medical Center
Carly Hoffman	Lucile Packard Children's Hospital Stanford University
Kendra Alanis	Methodist Children's Hospital of South Texas
Pagette Callender	
Angela Crowder	
Carina De La Pena	
Candice Escobedo	
Conschetta Wright	
Amy Goza	Midwest Children's Cancer Center
Jeannie Brown	Miller Children's Hospital
Timotius Budiwardoyo	
Sara Vang	
Marjorie Salas	Mount Sinai Medical Center
Virginia Haisten	Natalie W Bryant Cancer Center
Diane Marshall	
Laura Sanders	
Heather Bell	Nationwide Children's Hospital
Jacqueline Henderson	Naval Medical Center - San Diego
Dana Collins	Nemours Children's Clinic - Jacksonville
Wendy Doyle	Nevada Cancer Research Foundation CCOP
Stephen Funk	
Jacqueline Garcia	
Marilyn Holley	
Lisa Stefanski	
Jocelyn Bell	Princess Margaret Hospital for Children
Jessica Barsom	Rady Children's Hospital - San Diego
Diane Cornett	Rainbow Babies and Childrens Hospital
Meredith McMahan	Riley Hospital for Children
Sarah Chapman	Rocky Mountain Hospital for Children-Presbyterian Saint Luke's Medical

Emily Browne	Saint Jude Children's Research Hospital
Ruth Cain	Saint Mary's Hospital
Victoria Champagnie	
Lisa Cox	
Stephanie Hill	
Cynthia Kihei	
Elizabeth Mathew	
Nicole Borgrud	Sanford Medical Center-Fargo
Jennifer Dolalie	
Tami Johnson	
Susan Marquart	
Kimberly Rasmussen	
Cynthia Vingelen	
Shari Nickel	Saskatoon Cancer Centre
Willard Jones	Scott and White Memorial Hospital
Brian Hart	Sinai Hospital of Baltimore
Kristina Bennett	State University of New York Upstate Medical University
Yvonne Dolce	
Maria Hartman	
Jenelle Vargulick	
Nicole Cori	The Children's Hospital at Westmead
Alison Steeves	The Montreal Children's Hospital of the MUHC
Carly Turner	University of Alabama at Birmingham
Lauren Speirs	University of South Alabama
Lloyd Gray	Virginia Commonwealth University
Carrie Sitterson	
Juliann Kiefer	Washington University School of Medicine
Colleen Ward-Mujica	Weill Medical College of Cornell University
Katherine Fernandez	Women's and Children's Hospital-Adelaide
Susan Anderson	Yale University
Elizabeth Palchick	
Alexandra Wanat	
Upgraded Member - Full	**Institution**
Julie Isbell	Vanderbilt University

CHILDREN'S ONCOLOGY GROUP

Nursing Newsletter

New Nursing Appointments to Committees as of November 2012

New Nursing Appointments to Committees as of November 2012	
Wendy Fitzgerald	ANBL1232: Response- and Biology-Based Therapy for Patients with Non-High-Risk Neuroblastoma
Renee Klenke	ADVL1321: A Phase II Trial of Imetelstat in Children with Refractory Solid Tumors

CHILDREN'S ONCOLOGY GROUP

Nursing Newsletter

In the Literature…Nursing Publications

Courtesy of University of Mississippi Medical Center

Fernandez CV, Ruccione K, Wells RJ, Long JB, Pelletier W, Hooke MC, Pentz RD, Noll RB, Baker JN, O'Leary M, Reaman G, Adamson PC, Joffe S. Recommendations for the Return of Research Results to Study Participants and Guardians: A Report From the Children's Oncology Group. J Clin Oncol. 2012 Oct 29. [Epub ahead of print]

Cullen P, Moore I. Functional Status, Behavior, Executive Function and Quality of Life in Children Undergoing Treatment for Standard-Risk Medulloblastoma: The Children's Oncology Group Nursing Experience. Neuro-Oncology 14:i123, 2012.

Murphy K. Making the Most of the Children's Oncology Group Family Handbook for Children with Cancer. APHON Counts 2012;26(2):10-11.

Dunaway RP. Importance of Quality Data in Clinical Research. APHON Counts 2012;26(3):6-7.

CHILDREN'S ONCOLOGY GROUP

Nursing Newsletter

2012-2013 Meetings and Educational Opportunities

February 6-8 Atlanta, GA
7th Annual ANA Nursing Quality Conference

February 14-16 Huntington Beach, CA
American Psychosocial Oncology Society 10th Annual Conference

March 13-16 New Orleans, LA
American Academy of Hospice and Palliative Medicine/Hospice and Palliative Nurses Association Annual Assembly

April 6 - 10 Washington, DC
American Association for Cancer Research Annual Meeting

April 9-13 Minneapolis, MN
Children's Oncology Group meeting (invitation only)

April 11-14 Nashville, TN
Society for Pediatric Nurses Annual Convention

April 17-20 Orlando, FL
National Association of Pediatric Nurse Practitioners 34th Annual Conference on Pediatric Health Care

April 25-28 Washington, DC
Oncology Nursing Society Annual Congress

May 15-17 Minneapolis, MN
Association of Pediatric Oncology Social Workers Annual Conference

May 31-June 4 Chicago, IL
American Society for Clinical Oncology Annual Meeting

July 22-26 Prague, Czech Republic
Sigma Theta Tau 24th International Nursing Research Congress

September 19-21 Louisville, KY
APHON 36th Annual Conference

September 25-28 Hong Kong, China
45th Congress of the International Society of Paediatric Oncology

October 8-12 Dallas, TX
Children's Oncology Group meeting

CHILDREN'S ONCOLOGY GROUP

Nursing Newsletter

News You Can Use: End-of-Life Care Planning for Adolescents and Young Adults

A new study, published in Pediatrics and conducted at the Pediatric Oncology Branch of the National Cancer Institute and Georgetown University Hospital, evaluated the use of end-of-life advanced planning guides for adolescents and young adults (AYAs) between 16 and 28 years of age. A tool developed for the AYA population, "My Thoughts, My Wishes, My Voice" was compared to the "Five Wishes" tool previously developed to guide adult advanced care planning. The researchers found that the majority of study participants preferred the AYA-focused tool compared to the adult planning guide. The researchers used the feedback from study participants to tailor a new end-of-life planning guide, "Voicing My Choices" for AYAs, which focuses on the AYA's decisions related to four basic areas: (1) Medical treatment, (2) Palliative care, (3) Information-sharing with family and friends, and (4) How they would like to be remembered.

Further information about the study is available at: http://www.ncbi.nlm.nih.gov/pubmed/23045560 and the "Voicing My Choices" AYA end-of-life planning guide is available at: http://www.agingwithdignity.org/voicing-my-choices.php

Reference:

Wiener L, Zadeh S, Battles H, Baird K, Ballard E, Osherow J, Pao M. Allowing Adolescents and Young Adults to Plan Their End-of-Life Care. Pediatrics. 2012 Nov;130(5):897-905.