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Courtesy of Children's Hospitals and Clinics of Minnesota

Editorial Board:

Editor: [Kathy Ruccione](#)

Web designer: [Dave Amodei](#)

COG Nursing Mission:

The mission of the COG Nursing Discipline Committee 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

Link to Application for Nursing Discipline Involvement (which is on the Nursing Education Subcommittee page, <https://members.childrononcologygroup.org/Disc/nursing/Education.asp>)

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It was hard to believe it was springtime when I looked out the window in Minneapolis during the recent COG meeting. To



my California eyes, it was quite beautiful – even other-worldly. But not the birds-of-paradise blooming in the front yard type of spring view I'm used to! In the meetings, though, ideas and plans were blooming, and you'll get a taste of that in this issue of the COG Nursing Newsletter, particularly in the COG BLOG postings from your Nursing Discipline Subcommittee chairs and your elected Members-at-Large.

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 selections of evidence-based practice projects, an update on the return-of-results web portal, as well as a call for applications for the position of Clinical Trials

Subcommittee Co-Chair. You'll also find a profile of Maureen Haugen, your Nursing Education Chair. As always, I look forward to hearing from you with any suggestions or feedback about the COG Nursing Newsletter.

Whatever the weather is like where you are, I hope that you can enjoy the promise of spring as a fresh start at something, an opportunity to stretch and grow, and a time to feel reinvigorated for the important work you do.

Kathy Ruccione, MPH, RN, CPON®, FAAN



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From the Nursing Discipline Chair

Dear COG Nursing Colleagues,

In this year's first issue of Cancer Nursing, Dr. Pamela Hinds and her colleagues in the Department of Nursing Research and Quality Outcomes at Children's National Medical Center in Washington, D.C. published a poignant editorial¹ in which they persuasively argue the importance of declaring a legacy in oncology nursing. A legacy, they explain, "is an explicit statement of a plan to achieve 'that which is better' in oncology....to make a lasting positive change in the state of what is."¹

Over the past 3 years, your COG Nursing Discipline leadership has led a focused effort to identify important gaps in pediatric oncology nursing science, which culminated with the recent publication of COG Nursing's 5-year Blueprint for Research.² In this document, I believe we have clearly declared the legacy of the COG Nursing Discipline, which focuses in large part on the following aims:

- Supporting the conduct of research within the COG
- Identifying best practices in protocol-related nursing care and developing instructional programs for COG nurses to disseminate state-of-the art information regarding protocol-related care
- Understanding, testing, and implementing best practices in patient/family education across the pediatric cancer continuum, and
- Understanding the burden of illness-related distress experienced by pediatric oncology patients and their family caregivers, and developing targeted interventions to improve their resilience and overall well-being.

According to Hinds et al., "A legacy is not what our patients, teammates, colleagues, or our students expect us to give – rather it is what we want to give to them based on our interpretation of our interactions with these groups about what needs to be better; it is about what inspires us most regarding these identified needs"¹ [emphasis added].

Together, we are stronger than any of us can ever be individually; none of us can do this work alone. I hope you are inspired to join with your COG Nursing colleagues to give our patients, families, team members, and future pediatric oncology nurses "that which is better" – to help us "make a lasting positive change." I challenge each of you to become part of the COG Nursing Discipline's legacy by getting involved in whatever capacity you are able. You will see our aims featured prominently in all we are doing within COG Nursing over the next several years, as we move forward together toward achieving them.

For every patient and family whose lives you touch, for every life-sustaining dose of medication you give, for every element of data you collect, for every hand you hold and every tear you wipe, for your well-honed skills and your tireless work, you are carrying out the work of the COG Nursing Discipline every day....and I thank you sincerely for all that you do. Together, we have declared our legacy - I now look forward to achieving it with all of you.

Most sincerely,



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



Wendy Landier, COG Nursing Chair

¹ Hinds PS, Engh EP, Keller S, Kelly KP, Lee MA, Menard J, Roberts-Turner, R. Declaring your legacy of excellence in oncology. Cancer Nurs 2013 Jan-Feb; 36(1):3.

² Landier W, Leonard M, Ruccione K, on behalf of the COG Nursing Discipline Committee. Children's Oncology Group's 2013 Blueprint for research: Nursing discipline. Pediatr Blood Cancer 2013 Jun;60(6):1031-6.

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Profiles in COG Nursing: Maureen Haugen, RN, MS, CPNP, CPON®



Maureen Haugen is your COG Nursing Education Subcommittee Chair. To those she has worked with to plan and conduct the COG Educational Track at the APHON conferences, she is known as the epitome of organization. Always on time – if not early – to meet deadlines, her planning skills and attention to detail have translated the Educational Track vision into reality – a successful effort that has consistently been very well reviewed by those who have attended. Maureen's determination and willingness to tread bravely into the world of multimedia have also made the Educational Track presentations accessible by posting them on the COG nursing webpages. An expert clinician, Maureen is an APN in oncology on the Hematologic Malignancy Team, and the APN Manager in Hematology, Oncology, Stem Cell Transplant at the Ann & Robert H. Lurie Children's Hospital of Chicago. She was selected as a 2011 Nurse of the Year by the Leukemia Research Foundation, having been nominated by the mother of one of her patients who described how the faces of the children in clinic "light up when she comes to get them from the waiting room, indicative of their love for her." Maureen also received the APHON award for Excellence in Pediatric Hematology/Oncology Education in 2009. Maureen combines the core skills of clinical expertise and a passion for teaching that characterize the true clinician-educator. Outside of work, Maureen likes to work out, doing yoga, weight lifting or cardio exercising, which she says get her mind and body clear and refreshed for a new challenge.

Here we talk with Maureen about her work and volunteer activities with COG.

Could you tell us something about your background? Where did you complete your nursing education? I originally went to the University of Iowa and then transferred to Northwestern University where I received my BSN. I was in the first class of the nursing school there! Once I finished my undergraduate degree, I decided to go onto graduate school and received an MS in Parent-Child Nursing from the University of Michigan.

What factors influenced your decision to become a nurse practitioner? My father, a professor at Northwestern University at the time, first encouraged me to go on for graduate education soon after I finished my BSN, saying that I would have more time and flexibility for school at that stage of my life. Once I was in my Master's program to become a CNS at the University of Michigan, my advisor encouraged me to follow the PNP track. It was new at the time, and she said that it would give me more career opportunities. I am thankful to both of them many times over for giving me this advice!

How long have you been in pediatric oncology? What brought you to this specialty? What keeps you in it? I have been in pediatric oncology for 24 years. I was drawn to this specialty when I was in graduate school and did a clinical rotation at the University of Michigan (U of M). Marcia Leonard and Mary Waskerwicz were my preceptors and I wanted to be just like them! I was inspired by their dedication and passion for caring for children with cancer and their families. When I graduated, there were no jobs in pediatric oncology, so I took a position as a CNS in

Immunology/Rheumatology at Children's Memorial Hospital (CMH), Chicago. When Dr. Sharon Murphy arrived from St. Jude Children's Research Hospital to become the division head of oncology at CMH I asked her if she might be interested in creating a job for a PNP. She had worked with many PNPs in the past and was willing to break new ground at CMH. I ended up breaking new ground with her support as an oncology PNP at CMH! What keeps me in the specialty? The nurses, physicians, and other staff I work with are outstanding. We all are on a mission together to cure cancer. And we could not do what we do without the great families dedicated to caring for these children.

What has it been like to be the Chair of the Nursing Education Subcommittee so far? It has been a fantastic experience learning how an international cooperative group for clinical trials works and the integral part that the Nursing Discipline plays in this research. I have also met and collaborated with many people from all across the country and have enjoyed discovering how much we have in common.

What things have you been responsible for/what's the scope of the job? I am responsible for nursing education as it relates to clinical trials. This has encompassed a yearly COG Educational Track at the annual APHON conference with a preconference workshop and 4 concurrent sessions. Each year I have led a task force in developing the content for the COG Track and inviting speakers to lead each session. I have guided the speakers through the process of producing professional quality presentations, and then have been able to have these sessions posted as multimedia files with downloadable handouts on the COG nursing webpages.

What kinds of experiences in COG or elsewhere have helped you the most in this position? What has helped me most in this position is all of the members of the COG nursing leadership who are so willing to mentor and support me. I also will add that Dr. Sharon Murphy has been a huge influence in developing my passion for improving the outcomes and lives of children with cancer through clinical trials.

What highlights of this experience will stay with you? Highlights of my COG experience are the people I have met, nurses and physicians; the leadership skills I have developed in my role; friendships formed; and all of our accomplishments! The COG nursing leadership is from many different geographic areas and has come together with similar personal and professional goals, namely to provide the most skilled care for children being treated for cancer on clinical trials, and ultimately to cure cancer altogether.

What are you most proud of? I am most proud of how accomplished the COG Educational Tracks at APHON have become, and how well received they have been by the COG nursing and APHON members.

When you look back on this experience in the future, what do you hope you will have accomplished in your term of office? I hope that, through multiple professional educational formats, I have helped the COG nursing members to learn more about clinical trials, and understand how to better care for their patients who are enrolled on clinical trials. I also hope that I have given the COG nursing membership more opportunities to become involved in COG.

Anything else you'd like to share about your experiences in COG Nursing, COG or peds oncology? Or life in general? If I could share a few words of wisdom with other nurses, it would be to reach beyond your work setting to become involved in COG or another professional organization. This experience has positively changed me personally and professionally!

WHAT DOES THE COG EDUCATION SUBCOMMITTEE CHAIR DO?

- Serve on the Nursing Discipline Steering Committee
- Chair all Nursing Education Subcommittee meetings
- Fully support the mission and values of the COG and the Nursing Discipline
- Lead the development, implementation and evaluation of continuing education programs and materials related to pediatric oncology clinical trials nursing
- Collaborate with the Member-at-Large responsible for patient/family/public education to assure coordinated education strategies

You can reach Maureen by email at mhaugen@luriechildrens.org

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New Disease Committee Nurse appointments

At the recent COG Nursing Steering Committee meeting in Minneapolis, I announced some changes in the Disease Committee Nurse (DCN) appointments. Debbie Woods from Washington University has completed her term as DCN for the NHL Committee and Faye Willen from Nationwide Children's Hospital will assume this role beginning with the Fall COG meeting. Stacy Senn, the ALL DCN from Children's Healthcare of Atlanta, is also completing her term this fall, and Christine Yun from Miller Children's Hospital will become the ALL DCN starting this fall. The COG Nursing Steering Committee members expressed great gratitude to Debbie and Stacy for their contributions to their respective disease committees and for their role in COG nursing leadership. The DCN term of service is 5 years, and there will be other upcoming changes as DCNs complete their service and new appointments are made. Be on the lookout for those announcements.

*Joy Bartholomew, FNP-BCCo-Chair,
Nursing Clinical Trials Subcommittee*

Nursing education: the COG Track at APHON and beyond...

I want to share several updates from the Nursing Education Subcommittee with you. First, the presentations in multimedia format from the COG Educational Track at the APHON 2012 Annual Conference in Pittsburgh are now posted on the COG Nursing webpages! If you weren't able to attend the conference, the presentations are a terrific learning opportunity. And if you did attend, the presentations are a great way to review.

We are also well on our way to providing another exciting COG Educational Track at the APHON 2013 Annual Conference in Louisville! This year's conference theme is Leading with Courage – Caring with Confidence. Members of the Nursing Steering Committee are in the process of working with the speakers as they prepare their materials for their COG sessions. The Our preconference workshop topic is *Confidently Caring for Children with Brain Tumors on COG Clinical Trials*. Concurrent session topics include: *Confidently Caring for Children Receiving Ch14.18 on a Clinical Trial*, *Confidently Caring for Children with High Risk ALL: The COG AALL1131 Study*, *Confidently Caring for a Child with Down Syndrome on a Clinical Trial*, and *Clinical Trials and You: What You Need to Know to Confidently Care for Patients and Families*. Hope to see you at the APHON Conference! We plan to post these presentations on the COG Nursing webpages, as well.

We are always looking for speakers and – most importantly – topic ideas for future COG Educational Track at APHON sessions, as well as for the Nursing Plenary Session at the Fall COG meetings. If you have ideas for topics or speakers, suggestions to support clinical trials-related nursing education, or want to volunteer, please contact me at mhaugen@luriechildrens.org. I'd love to hear from you!

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

Best practices in patient/family education

As co-chairs of the nursing research sub-committee, we (Kathy and Casey) also serve on the COG Nursing Discipline Steering Committee. In the steering committee, we have discussed the need to advance our knowledge about how to effectively teach families treated on clinical trials. We know pediatric oncology nurses focus a lot of their time and effort on teaching families so they can safely care for their child at home. As we begin to explore the evidence on the best ways to teach, we are discovering that there isn't a lot out there specific to pediatric oncology.

We talked in our steering committee about wanting to identify the most effective teaching methods. If they can't be identified through the published literature, then we want to test (research) different methods. Additionally, how do we measure our teaching outcomes? For example, do we know parents understand what to do for a fever when their child is neutropenic because they call in within the hour? We also discussed that there is a difference in what we expect parents to know and act on shortly after diagnosis versus later in treatment when they have more experience and are not in crisis.

We will continue to examine current research as well as look to other diseases for their research on teaching newly diagnosed patients (e.g., pediatric diabetes). Stay tuned as this research priority develops!

*Casey Hooke, PhD, RN and
Kathy Kelly, PhD, RN
Co-Chairs, Nursing Research Subcommittee*

Clinical Trials Subcommittee: Leadership Opportunity

Joy Bartholomew announced that she will be stepping down as the Chair of the Clinical Trials Committee later this year. Joy has been very active member of the Nursing Steering Committee for many years and we are all sad to lose her, but she assures us she will remain very active in COG, especially within the neuroblastoma committee. Joy will be a hard act to follow, but nurses who are interested in this role should see the [call for applications for this position](#)

Joy and Marcia continue to work on refining the disease committee and protocol nurse job description. This is being done to help improve the satisfaction of nurses in these important roles and to help our physician colleagues understand how valuable the protocol nurse's experience can be when designing and carrying out clinical trials. We are starting to plan the protocol specific presentations for the Fall Clinical Trials session—please let us know if you have any ideas for specific studies you would like to see highlighted.

The family protocol summaries (FPS) have undergone a slight revision in style, as requested by Dr. Adamson and the COG leadership. The FPS are now shorter in length and highlight the study question and aims—rather than provide an overall summary of the study. The FPS are being revised systematically; the cancer control studies are complete and posted <http://childrensoncologygroup.org/index.php/family-protocol-summaries> on the COG public web site. The FPS is an excellent tool to give to families at diagnosis who are eligible for a clinical trial. The FPS editing committee currently consists of Marcia Leonard, Kathy Ruccione, and Liz Bell (Kaiser Los Angeles Medical Center). Karina Black (Alberta Health Services), and Jen Hudson (Children's Mercy, Kansas City) have been active and fabulous members of the committee (thanks so much to you both!) but will be stepping down. If you like to write and edit, we would LOVE to have you join our group. Work commitment involves writing/revising one FPS as well as a monthly on-line editing conference call. Please contact marcia@umich.edu if you would like to join or even if you would like to learn more about it. This is a great way to get more involved in the COG nursing committee.

*Marcia Leonard, RN, PNP
Co-Chair, Clinical Trials Subcommittee*

Patient/family education materials

I'm happy to say that the COG Family Handbook, 2nd edition, is being widely used across COG institutions. The downside of that popularity, though, is that the supply of English and Spanish printed copies was quickly exhausted. (Copies of the French translation are still available for COG institutions to order.) At the Nursing Steering Committee meeting, we discussed various avenues to pursue to secure funding for future printing of the Handbook. In the meantime, we recently added high-resolution files of the Handbook to the COG public website for institutions that choose to print their own copies. The high-resolution files provide more efficient and higher quality printing.

The Nursing Steering Committee also discussed new ways to meet the needs of the adolescent and young adult population with effective educational materials. Stay tuned for announcements on this topic!

You can find the COG Family Handbook posted here:

<http://www.childrensoncologygroup.org/index.php/cog-family-handbook>

*Katy Murphy, BSN, RN
Member-at-Large*

Member activities on the horizon

As your new member-at-large, I am looking forward to implementing several exciting ideas that were discussed at the Spring COG meeting. One of the projects is to set up a listserv to facilitate communication among the institutions' Responsible Investigator (RI) nurses. Our hope is that this would open lines of communication among RI nurses and would be a great forum for discussions with one another. There was also discussion about ways to continue to encourage nursing involvement and keep in touch with nurses who have shown interest in becoming more active within the organization. We will begin to monitor our database of volunteers on a monthly basis and make sure we are keeping members updated as quickly as possible when new opportunities for involvement arise. We want to make the best match between the many talented nurses who have expressed interest and the possible opportunities so please know that we are trying to implement a more streamlined and effective communication process. We also discussed ideas for the fall COG meeting to help as many new members as possible get acquainted with how this meeting is run and how it is effectively navigated. We recognize that it usually isn't possible to schedule an orientation meeting at the beginning of the COG schedule of meetings. We are exploring ways to give first-time attendees some anticipatory guidance about the meeting before they arrive. In my new role, I'm looking forward to meeting interested COG nurses at the APHON Conference prior to the fall meeting and making myself available to share information about COG Nursing. If I can answer any questions at any point please contact me at Wofford_j@kids.wustl.edu.

*Jennifer Wofford, APRN, PNP-BC
Member-at-Large*

The COG BLOG features highlights from COG Nursing meetings and activities. If you have something COG Nursing-related that you'd like to blog about or want to comment on this issue's postings, please send an email query to Kathy Ruccione at kruccione@chla.usc.edu. We welcome your thoughts and ideas!

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Rhabdomyosarcoma (RMS) is a malignant soft tissue tumor of mesenchymal origin. In the United States, the incidence is 4.5 per 1 million children, accounting for approximately 3% of cancers in children and 2% in adolescents/young adults. Factors that affect prognosis are age, histology, site of origin, resectability, metastasis and biological characteristics of the tumor cells. Historically, the majority of children (80%) with recurrent RMS have had an unfavorable prognosis, with an overall survival rate at five years of approximately 10%.

ARST0921 is a Phase II Children's Oncology Group (COG) randomized trial, which opened in October 2010 for patients with RMS in first relapse or with primary refractory disease.

- The primary study goal is to determine the feasibility of administering bevacizumab (B) or temsirolimus (T) in combination with vinorelbine (V) and cyclophosphamide (C) in patients with recurrent RMS, along with evaluating event-free survival in patients with relapsed/refractory RMS treated with B + VC compared to those treated with T + VC.
- Secondary goals include comparing response rates after two cycles between the two treatment arms and testing blood and tumor tissue for biological markers.

This trial is available for any child or young adult less than 30 years of age with first relapse or primary refractory RMS that was histologically proven at initial diagnosis. It requires a reservation through COG prior to consent and enrollment. Inclusion criteria that must be evaluated prior to study entry include performance status, life expectancy, prior therapy, and organ function requirements. Patients must have fully healed from any surgical procedure prior to enrollment.

DRUG NAMES IN THIS STUDY	
Generic Name	Trade Name
bevacizumab	Avastin
temsirolimus	Torisel
vinorelbine	Navelbine
cyclophosphamide	Cytosan (and others)

At study entry, patients will be randomly assigned to one of two arms: VC+ B (Arm A) or VC + T (Regimen B). Each cycle consists of 21 days with a maximum of 12 cycles in the absence of disease progression. Day 1 of a cycle begins once the ANC is greater than/equal to 750 and platelets greater than/equal to 75,000. In both treatment arms, vinorelbine is given on day 1 and 8, with cyclophosphamide given on day 1 with mesna rescues. In Arm A, the bevacizumab is given on day 1. In Arm B, the temsirolimus is given on days 1, 8, and 15. A myeloid growth factor is to be initiated on day 9 (24 hours after the day 8 vinorelbine). Prior to enrollment, it is strongly suggested that a central venous catheter be inserted for venous access due to the risk of extravasation with vinorelbine.

Nursing considerations for this regimen consist of concomitant therapy restrictions. Drug interactions with CYP450 enzyme inducer/inhibitors have been reported with vinorelbine and temsirolimus (a comprehensive list can be found at <http://medicine.iupui.edu/clinpharm/ddis>). Other agents to avoid include St John's Wort, an over-the-counter herbal preparation used for depression, which may decrease temsirolimus plasma concentrations, and grapefruit juice, which may increase temsirolimus plasma concentrations. Special precaution is to be used with bevacizumab and surgical procedures. A black box warning includes the risk of wound healing complications and gastrointestinal perforation. No patient should have a planned major surgical procedure within 28 days of receiving bevacizumab or the dose should be suspended. After a major surgery, no bevacizumab dose should be given for at least 28 days and until the surgical wound is healed; after a minor surgical procedure no bevacizumab dose should be given for at least 7 days and until the surgical wound is fully healed. Radiation therapy, if used for local tumor control, cannot occur until after cycle 2, and both bevacizumab and temsirolimus should be held during radiation therapy.

Information resource:

A youth information sheet for this study, written in plain language, is posted with the protocol on the COG member website.

Donna Plaxe MSN, PNP-PC, CPON

Inpatient Advanced Practice Nurse

Division of Pediatric Hematology/Oncology

The Cancer Institute of New Jersey &

Bristol-Myers Squibb Children's Hospital New Brunswick, NJ

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New Nursing Members

WELCOME TO 145 NEW* AND UPGRADED COG NURSE MEMBERS! (*since the December Nursing Newsletter)	
New Member	Institution
Melinda Lippert, Vanessa Slobogian	Alberta Children's Hospital
Whitney Barnes, Shelley Blount, Aimee Crowe, Heather Cundy, Mary Hennessy, Jonathan Herman, Tammy Hieber, Jennifer Jandl, Kelly Lawless, Jana Marra, Denelle Sheridan, Julie Shusko	All Children's Hospital
Tammy Navigato, Arpita Patel	Ann and Robert H Lurie Children's Hospital of Chicago
Susan Pilat	Baylor College of Medicine
Samantha Hayes	CancerCare Manitoba
Lindsay Brefeld	Cardinal Glennon Children's Medical Center
Meghan Burns, Jane Perlestein	Cardon Children's Medical Center
Tracy Fukes, Alissa Green, Patricia Hagan-Jones, Cathryn Jordan, Amy Kelly	Carolinas Medical Center/Levine Cancer Institute
Sara Bashor, Leslie Landon	Children's Healthcare of Atlanta - Egleston
Maria Padilla, Sia Vang	Children's Hospital Central California
Katie Nadeau, Kerri Skoruppa	Children's Hospital Colorado
Beth Roberts	Children's Hospital Medical Center of Akron
Kelly Fons	Children's Hospital Los Angeles
Anne Grifo, Retha Randall	Children's Hospital of Philadelphia
Ashleigh Clore, Heather Trivett	Children's Hospital-King's Daughters
Lee Jackson, Rebecca Kahler, Catherine (Trinka) O'Fallon, Danica Stull	Children's Mercy Hospitals and Clinics
Lynne Showers	Dana-Farber Cancer Institute
Kristina Harrison, Annika Krupp, Susan Russo	Dell Children's Medical Center of Central Texas
Gina Dovi, Joanne Esposito, Melanie Nycz, Jessica Raimo	Hackensack University Medical Center
Joginder Sandhu	Kaiser Permanente-Oakland
Diane Burnett, Elizabeth Chaney	Kosair Children's Hospital
Karin Colunga	Loma Linda University Medical Center
Mary Lee	Loyola University Medical Center
Michele Santilhano	Lucile Packard Children's Hospital Stanford University
Tiffany Butler, Nicole Jordan, Michele Pedulla, Jennifer Pelley	M D Anderson Cancer Center
Dena Weinmann	Mayo Clinic
Anita Voorhees	MedStar Georgetown University Hospital

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Amelia DeRosa	Memorial Sloan Kettering Cancer Center
Barbara Anderman, Cynthia Boehmer, Linda McKay, Julie Parsons, Colleen Stebe, Laura Walker	Mercy Hospital Saint Louis
Kimberly Arrellano, Ellen Elzinga, Marian Fisher, Beth Millican	Methodist Children's Hospital of South Texas
Laura McNally	Midwest Children's Cancer Center
Christine Briggs, Maxine Johnson, Marylyn Paulsen	Miller Children's Hospital
Danielle Grabinski	Morristown Medical Center
Ryan Adams	Nationwide Children's Hospital
Abbey Busch	Nemours Children's Clinic - Jacksonville
Janice Cavanaugh, Jennie Hall, Holly Jones	Nemours Children's Clinic - Pensacola
Laurie Deublein	Phoenix Childrens Hospital
Hannah Yow	Presbyterian Hospital
Samantha Kar	Providence Sacred Heart Medical Center and Children's Hospital
Heather Driscoll, Lindsey Faris, Katherine Frederickson, Kristen Olson, Andrea Omsberg	Rady Children's Hospital - San Diego
Amber Burke	Raymond Blank Children's Hospital
Heidi Abendroth, Caitlin Montcrieff	Rhode Island Hospital
Jayne Harrison	Royal Children's Hospital
Ruth Kuhrts	Saint Jude Midwest Affiliate
Heather Andrade	Saint Luke's Mountain States Tumor Institute
Mary Prokop	Saint Mary's Hospital
Shira Nusbaum	Saint Peter's University Hospital
Samantha Porter	Sanford Medical Center-Fargo
Heather Cattet	Saskatoon Cancer Centre
Erin Sherman	Sinai Hospital of Baltimore
Bridget Smith	Starship Children's Hospital
Mark Ritter	State University of New York Upstate Medical University
Debra Cunningham, Jessica Whitlock	The Children's Medical Center of Dayton
Louise Colacci, Johanne Soucy	The Montreal Children's Hospital of the MUHC
Gina Covelli	The Steven and Alexandra Cohen Children's Medical Center of New York
Anastassia Dubov	University of Alberta Hospital
Carol Oldridge	University of Arkansas for Medical Sciences
Martina Mooney, Kelly Neale, Lisa Tsang	University of California San Francisco Medical Center-Parnassus
Caitlin Beaudoin	University of Chicago
Meghan Eaton	University of Massachusetts Medical School
Emily Brueggen, Lauren Clifford, Gretchen Skog	University of Minnesota Medical Center-Fairview
Breckin Johnson, Christen Quarles, Katie Williams	University of Mississippi Medical Center
Tammy Burroughs	University of Nebraska Medical Center

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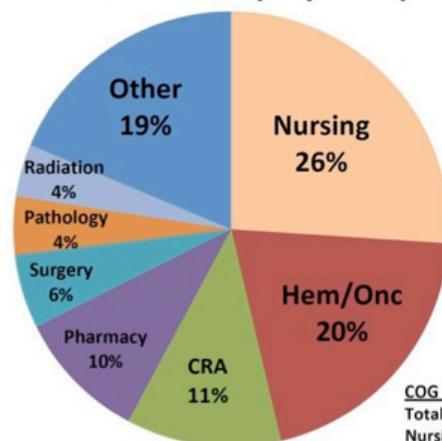
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Leslie Peters	University of New Mexico
Amy Rosenbohm	University of South Alabama
Carol Jenkins, Sara Olivarri	University of Texas Health Science Center
Jessica Bailey	University of Texas Southwestern Medical Center
Karen Parks	University of Virginia
Hannah Wright	Vanderbilt University
Amy Pope	Wake Forest University Health Sciences
Latresha Bowers, Bridgett Gildehaus, Jodi Kipp, Aimee Nelson, Susan Pardeshi, Britanny Richardson, Carolyn Schenck, Robin Stegall, Heather Taylor, Alison Towerman	Washington University School of Medicine
Cristy Ward	Yale University
Upgraded to Full Member	Institution
Nancy Hart	Children's Hospital Los Angeles
Molly Brickler	Midwest Children's Cancer Center
Catherine Fiona Macpherson	Seattle Children's Hospital

COG Membership by Discipline



COG Membership – April 2013
Total Number of COG Members – 8780
Nursing Discipline Members – 2285

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New Nursing Appointments to Committees as of April 2013

NEW NURSING APPOINTMENTS TO COMMITTEES AS OF APRIL 2013

Christine Yun	Lymphoid Disease Committee
Kay Blyth	ACCL 1333: A Phase III Apixaban Study

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COG NURSING LEADERSHIP OPPORTUNITY

The Children's Oncology Group Nursing Discipline invites your application for the open position of **Co-Chair of the Clinical Trials Subcommittee**. This position is at the heart of COG clinical trials nursing and presents a unique opportunity for nurses interested in being part of the leadership team for the dynamic COG Nursing Discipline.

Description of Role: Co-Chair, COG Nursing Clinical Trials Subcommittee

- Works with the Co-Chair, Nursing Clinical Trials, and the Nursing Discipline Steering Committee to:
 - Facilitate communication with the COG Membership Committee and membership staff in the Group Operations Center about the COG membership application process
 - Lead the application/appointment process for nurses interested in working on COG protocol/disease committees
 - Foster professional growth and optimal contribution of nurses appointed to protocol/disease committees
 - Appoint task forces/work groups as needed to address nursing issues related to clinical trials participation
 - Collaborate with other Nursing Subcommittees to complete projects of mutual interest
- Maintains nursing clinical trials appointment database and provides timely, accurate data to the COG Nursing Steering Committee (e.g., about nursing requests for appointments, committee requests for nursing participation, appointments made).
- Plans and leads Nursing Clinical Trials Subcommittee meetings during COG meetings.
- Participates in monthly Nursing Steering Committee conference calls.
- Contributes to Nursing Discipline presentations, reports, proposals, newsletter and website.
- Maintains accountability for evaluating productivity and performance of Clinical Trials Subcommittee.

Qualifications:

- Full membership in COG
- Demonstrated experience participating in development and conduct of COG clinical trials (e.g., through service on protocol and/or disease committees)
- Demonstrated successful leadership skills
- Demonstrated ability, both oral and written, to communicate effectively with individuals and teams (nursing and multidisciplinary)
- Demonstrated ability to be self-directed and highly motivated
- Institutional support to conduct ongoing work related to this position (e.g., conference calls, emails, phone calls, database maintenance, and preparation of reports)
- Institutional support to attend COG meetings
- Commitment to a five-year term beginning in the fall of 2013

How to Apply

If you are interested in this opportunity, please submit a letter of interest with supporting documents (current CV/resume, 2 letters of recommendation, and a letter of institutional support (from your supervisor or PI, as applicable) guaranteeing work release time for conference calls, semi-annual COG meetings, and ongoing work related to this position). Please address these points in your letter:

- Describe your experience with pediatric oncology clinical trials on a local, regional, national level. Attach examples of related committee assignments, experience with protocols, and publications or presentations
- Identify the strengths you would bring to the role as Co-Chair and provide some examples of experiences that

have contributed to your leadership development

- Explain how you envision development of innovations in the Clinical Trials Subcommittee and the COG Nursing Discipline
- Describe your experience in working collaboratively to develop, conduct, disseminate, and evaluate projects relevant to COG clinical trials

Where/When to Send Your Letter of Interest

Please send your letter of interest and supporting documents to:

Wendy Landier, PhD, RN, CPNP, CPON®

Chair, COG Nursing Discipline

City of Hope

1500 E. Duarte Rd., DPS-173

Duarte, CA 91010

or email to: wlandier@coh.org

or fax to: 626-301-8983

Application deadline is June 14, 2013

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Landier W, Leonard M, Ruccione KS. Children's Oncology Group's 2013 Blueprint for Research: Nursing Discipline. *Pediatr Blood Cancer.* 2013 Jun;60(6):1031-6.

Reeve BB, **Withycombe JS**, Baker JN, **Hooke MC**, Lyons JC, Mowbray C, Wang J, Freyer DR, Joffe S, Sung L, Tomlinson D, Gold SH, **Hinds PS.** The first step to integrating the child's voice in adverse event reporting in oncology trials: A content validation study among pediatric oncology clinicians. *Pediatr Blood Cancer.* 2013 Jan 17. [Epub ahead of print]

Dahl, J. Communicating about Children's Oncology Group (COG) Research. *APHON Counts* 2012;26(4):6-9.

Olson, E. Nurses focus on prevention of oral mucositis in a Children's Oncology Group Study. *APHON Counts* 2013;27(1): 6,15.

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May 9-10 Lake Arrowhead, CA

Southern California Chapter of the Association of Pediatric Hematology-Oncology Nurses (SCAPON) 27th Regional Conference

May 15-17 Minneapolis MN

Association of Pediatric Oncology Social Workers Annual Conference

www.aposw.org

May 31-June 4 Chicago IL

American Society for Clinical Oncology (ASCO) Annual Meeting

www.asco.org/ascov2/meetings

June 5-7, 2013 San Diego CA

29th Association of Oncology Social Work Conference

<http://www.aosw.org/docs/AOSWConfBroch2013.pdf>

June 13-15, 2013 Memphis TN

13th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer

<http://www.stjude.org/register>

July 22-26 Prague, Czech Republic

Sigma Theta Tau 24th International Nursing Research Congress

www.nursingsociety.org

August 9-10, Chicago IL

Best of ASCO Chicago

<http://boa.asco.org/best-asco-chicago>

August 16-17, 2013, Los Angeles CA

Best of ASCO Los Angeles

<http://boa.asco.org/best-asco-los-angeles>

August 23-24, 2013, Boston MA

Best of ASCO Boston

<http://boa.asco.org/best-asco-boston>

September 19-21, 2013 Louisville KY

APHON 37th Annual Conference

www.aphon.org

September 25-28, 2013 Hong Kong, China

45th Congress of the International Society of Paediatric Oncology

www.kenes.com/SIOP

October 8-12, 2013 Dallas, TX

Children's Oncology Group meeting

www.childrensoncologygroup.org

November 6-7, 2013 Philadelphia PA

Alex's Lemonade Stand Nurse Researcher Workshop

<http://www.alexlemonade.org/nurse-researcher-workshop>

November 16-20, 2013, Indianapolis IN

Honor Society of Nursing, Sigma Theta Tau International

42nd Biennial Convention

<http://www.nursingsociety.org/STTIEvents/BiennialConvention/>

UPCOMING EDUCATIONAL OPPORTUNITIES

If you know of an educational offering that should be included in the COG Nursing Newsletter, please email the details (dates, location, name of conference/meeting, and website) to kruccione@chla.usc.edu

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2013 EBP Projects Announced

The COG Nursing Discipline evidence-based practice (EBP) initiative was launched with a presentation by Dr. **Marilyn Hockenberry** at the COG meeting in September 2011. This year, 12 proposals for EBP projects were submitted, up from four last year. From these, three were selected by a review panel.

- Identifying evidence-based practices to prevent/manage post lumbar puncture headaches in pediatric patients receiving intrathecal chemotherapy (Project leaders: **Rebecca Rusch**, RN, MSN, CPNP and **Christina Schulta**, RN, MS, CPNP, Medical College of Wisconsin)
- Establishing evidence-based guidelines for fertility preservation options for inclusion in treatment protocols for pediatric and adolescent patients diagnosed with cancer (Project leaders: **Alison Fernbach**, CPNP, Columbia University Medical Center and **Barbara Lockart**, CPNP, Lurie Children's Hospital).
- Developing evidence-based guidelines for standard hydration for children/adolescents with cancer receiving intravenous cyclophosphamide (Project leader: **Deborah Robinson**, DNP, APRN – Saint Louis Children's Hospital)



Marilyn Hockenberry, PhD, RN

Each team will proceed with a mentored review of the literature under the guidance of Drs. **Cheryl Rodgers**, **Marilyn Hockenberry**, and **Janice Withycombe**. This will be followed by a 2-day workshop this summer, led by Marilyn Hockenberry and supported by funding from the Alex's Lemonade Stand Foundation, which will bring these teams together at Duke University. Each team will finalize their evidence

summary and present their findings during the Nursing Discipline meetings at the Fall COG meeting in Dallas, and then develop manuscripts for submission to peer-reviewed journals. **Wendy Landier**, PhD, RN, COG Nursing Chair, summing up our EBP projects' status, said: "The quality of this year's EBP project proposals was outstanding, and the mentoring program and summer workshop are exceptional opportunities for developing expertise – warmest congratulations to all of the selected teams!"

What is evidence-based practice?

The conscientious, explicit, and judicious use of current best evidence in making decisions about care of individual patients (Sackett, *BMJ*, 1996).

Why is COG Nursing interested in EBP?

Evidence-based materials will enhance and facilitate the work of the group by providing guidance for addressing clinical issues that frequently arise while providing protocol-related care or follow-up.

Return of Results Web Portal Launched



The COG Return of Results (ROR) web portal is now "live" and can be accessed from the COG Public Website. Development of the ROR portal represents an important milestone for COG, and one that reflects the effort of a task force with wide-ranging representation from various disciplines, parents, and COG leadership and support staff. The searchable website allows registration by any interested person to be notified of new postings of lay summaries of results specific to the selected study. A PDF of Frequently Asked Questions is available under "Return of Results" on the left hand side of the landing page. A

PDF of a letter to be provided to COG study participants/families at the end of therapy and in follow-up clinic is also posted under "Return of Results." The letter explains how they may receive results of the research study.

It's important to note that for now, only registration for email notification of results is available, as study results have not yet been posted. Summaries of study results will be posted in a prospective manner beginning with COG phase II and III studies closed from 2010 forward. The sequence we have settled on is that the lay summary will be generated by the Nursing Discipline, reviewed by the PAC and by an expert in communications, and vetted for accuracy by the study chair and statistician. This part of the work is just beginning. The ROR web portal can be accessed via this link: <http://www.childrensoncologygroup.org/index.php/return-of-results>.

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Who would you ask about the administration of a drug being used in a new COG clinical trial? Who would you ask about the timing of PK studies for a COG clinical trial?

One of your best contacts for COG is the RI (Responsible Investigator) Nurse at your institution. The RI Nurse is the principal nursing resource about COG in each member institution. The RI nurse works with the CRA and the Principal Investigator (PI) to ensure institutional compliance in the conduct of each clinical trial. So while the RI nurse may not know the answer to every question about each clinical trial, he or she will know where to find the answers on the website or who to call.

Your RI nurse will know what nursing educational tools are available on the COG website. Would you like to become more active in COG, and possibly become a study committee nurse? The RI nurse can assist you in the application for nursing involvement in the COG Nursing Discipline.

The RI nurse is your local "go to" person for nursing in COG. Included here are the names of the RI nurse at each institution. If you don't already know your RI nurse, look for his/her name. Then get in touch with that person and introduce yourself. This could be the start of a very important relationship.

What if your institution is not listed? That means there is no RI nurse at your institution. As integral as this role is, it has occasionally been overlooked. But that is easy to remedy. Go to the PI of your institution and ask that an RI nurse be designated with the COG Membership Office. You could suggest someone (yourself?) who has a good working knowledge of COG nursing. It is as simple as that.

If you have any questions at all about RI Nursing please contact the Nursing Members-at-Large, Jenn Wofford at Wofford_j@kids.wustl.edu and Katy Murphy at kmurphy@chw.org

Carol Kotsubo, MPH, MS, APRN, OCN®, CPON®

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<u>Name</u>	<u>Institution</u>
Acosta, Carolyn	Oregon Health and Science University
Adams, Tara	Driscoll Children's Hospital
Adlard, Kathleen	Children's Hospital of Orange County
Agrippine, Karen	Lehigh Valley Hospital – Muhlenberg
Ahnberg, Michelle	Sanford USD Medical Center – Sioux Falls
Allen, Marni	Saint Lukes Mountain States Tumor Institute
Arevalo, Tara	Methodist Children's Hospital of South Texas
Arguello, Laurie	Loma Linda University Medical Center
Baker, Alison	The Children's Hospital at Westmead
Ballard, Jennifer	University of Kentucky
Baron, Patricia	Walter Reed National Military Medical Center
Bartholomew, Joy	Children's Mercy Hospitals and Clinics
Bashore, Lisa	Cook Children's Medical Center
Bauer, Sharon	State University of New York Upstate Medical University
Bayer, Lisa	Weill Medical College of Cornell University
Bayne, Ashley	University of Florida
Bell, Elizabeth	Southern California Permanente Medical Group
Betcher, Donna	Mayo Clinic
Bielek, Kathy	Cleveland Clinic Foundation
Bissette, Wendy	Carolinas Medical Center/Levine Cancer Institute
Bland, Elizabeth	Sydney Children's Hospital
Boucher, Lori	Dell Children's Medical Center of Central Texas
Bourne, Catherine	CancerCare Manitoba
Bowers, Anne	Mission Hospitals Inc.
Brandenburg, Candice	Mary Bridge Children's Hospital and Health Center
Breen, Kathleen	University of Illinois
Bui, Armi	Children's Hospital Los Angeles
Buitrago, Jennifer	Nevada Cancer Research Foundation CCOP
Bunnell, Dyane	Alfred I DuPont Hospital for Children
Carbone, Theresa	Roswell Park Cancer Institute
Cervone, Kelly Ann	New York University Langone Medical Center
Chan, Grace British	Columbia Children's Hospital
Chandler, Brenda	Texas Tech University Health Science Center – Amarillo
Chapman, Kristina	IWK Health Centre
Chavez, Cathy	University of New Mexico
Church, Patricia	Inova Fairfax Hospital
Clinton, Frieda	Our Lady's Children's Hospital
Conroy, AnnMarie	Floating Hospital for Children at Tufts Medical Center
Cord, Carlene	Hackensack University Medical Center
Corliss, Rosemary	Memorial Sloan Kettering Cancer Center
Cox, Stephanie	McMaster Children's Hospital at Hamilton Health Sciences
Cuffari, Christina	New York Medical College
Curry, Joan	Montefiore Medical Center – Moses Campus
Dahl, Jodell (Jody)	University of Minnesota Medical Center – Fairview
Darch, Liz	Princess Margaret Hospital for Children
DeCourcy, Mary Jo	Children's Hospital, London Ontario
DePazos, Alicia	Baptist Hospital of Miami

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Defrisco, Michelle	Ochsner Clinic Foundation
Delbrook, Cynthia	Mark O Hatfield-Warren Grant Magnuson Clinical Center
Dubov, Anastassia	University of Alberta Hospital
Dufour, Diane	Medical University of South Carolina
Dukes, Annette	Nemours Children's Clinic – Jacksonville
Eaton, Meghan	University of Massachusetts Medical School
Echtenkamp, Deborah	Medical City Dallas Hospital
Ekeroth, Veronica	Children's Hospital of Pittsburgh of UPMC
Fay, Kimberly	Madigan Army Medical Center
Fernandez, Maria	Miami Children's Hospital
Fey, Kristina	Children's Hospital Medical Center of Akron
Fisher, Beth	Georgia Health Sciences University
Fitzgerald, Wendy	Children's National Medical Center
Friedrich, Sharon	University of Wisconsin Hospital and Clinics
Friesen, Elizabeth	University of Vermont
Gagnon, Marie	Christine CHU de Quebec
Garcia Slanker, Jeanette	University of Miami Miller School of Medicine – Sylvester Cancer Center
Garcia-Frausto, Erica	University of Texas Health Science Center
Garrigan, Brenda	Marshfield Clinic
Gates, Jessica	Children's Hospital Central California
Geib, Kristi	University of North Carolina at Chapel Hill
George, Laurie	Eastern Maine Medical Center
Gibson, Maryanne	Cancer Centre of Southeastern Ontario at Kingston General Hospital
Goclik, Kelly	Saint John Hospital and Medical Center
Godfrey, Carol	University of Arkansas for Medical Sciences
Goes, Connie	Children's Hospital and Research Center at Oakland
Hadden, Carrie	Naval Medical Center – Portsmouth
Hager Carlucci, Dianne	Rhode Island Hospital
Harper, Alicia	West Virginia University Charleston
Harris, Nichol	Duke University Medical Center
Harris, Shirley	University of Oklahoma Health Sciences Center
Hart, Nicole	Children's Hospitals and Clinics of Minnesota – Minneapolis
Henderson, Kelly	Natalie W Bryant Cancer Center
Hershon, Linda	Hospital Sainte-Justine
Hesselgrave, Joy	Baylor College of Medicine
Hill, Deborah	Tripler Army Medical Center
Hoffman, Tanja	University of Texas Southwestern Medical Center
Houlahan, Kathleen	Dana-Farber Cancer Institute
Hudock, Michelle	Saint Vincent Hospital and Health Services
Hughes, Carla	Nationwide Children's Hospital
Hussong, Margaret	University of Rochester
Isbell, Julie	Vanderbilt University
James, Natalie	Starship Children's Hospital

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Kandsberger, Donna	Penn State Hershey Children's Hospital
Kean, Jeannine	University of Nebraska Medical Center
Kent, Patricia	Massachusetts General Hospital Cancer Center
Kokoszka, Andria	Presbyterian Hospital
Koshgarian, Janis	Albany Medical Center
Kotsubo, Carol	University of Hawaii
Kramer, Kelly	University of Chicago
Langevin, Stephanie	Childrens Hospital – King's Daughters
Leonard, Marcia	C S Mott Children's Hospital
Licata, Heather	Mercy Hospital St. Louis
Lively, Susan	Memorial University Medical Center
Lowery, Rachel	University of Mississippi Medical Center
Mahan, Rosemary	Stony Brook University Medical Center
Maloney, Anne Marie	Hospital for Sick Children
Marasciulo, Joan	Sinai Hospital of Baltimore
Marigliano, Christine	The Steven and Alexandra Cohen Children's Medical Center of New York
Mariniello, Marianne	Newark Beth Israel Medical Center
Martin, Amanda	East Tennessee Childrens Hospital
Martin, Rebecca	M D Anderson Cancer Center – Orlando
Martin, Shay	Rocky Mountain Hospital for Children – Presbyterian St. Luke's Medical Center
Matteson, Nancy	Maine Children's Cancer Program
Maxen, Charlene	Children's Hospital Medical Center of Akron
Meiman, Shawn	Kosair Children's Hospital
Milburn, Mehrzad	Rady Children's Hospital – San Diego
Miller, Heather	Broward Health Medical Center
Morales, Rose	Mount Sinai Medical Center
Morgan, Justine	Southern Illinois University School of Medicine
Musolf, Liz	The Toledo Hospital/Toledo Children's Hospital
Newman, Amy	Midwest Children's Cancer Center
Oglesby, Celeste	Seattle Children's Hospital
Olesen, Natasha	Allan Blair Cancer Centre
Olson, Britt	Phoenix Childrens Hospital
Ortiz, Laura	Lee Memorial Health System
Pedersen, Helen	Michigan State University Clinical Center
Pelayo, Luz	The University of Arizona Medical Center – University Campus
Peluso-LeMire, Emily	Connecticut Children's Medical Center
Perlstein, Jane	Cardon Children's Medical Center
Petee, Pamela	Mercy Children's Hospital
Picken, Stephanie	Raymond Blank Children's Hospital
Pike, Jennie	Riley Hospital for Children
Plaxe, Donna	UMDNJ – Robert Wood Johnson University Hospital
Powers, Janice	MedStar Georgetown University Hospital

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Roses-Landau, Jayne	City of Hope
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Roy, Nancy	Advocate Hope Children's Hospital
Sandin, Victoria	Providence Sacred Heart Medical Center and Children's Hospital
Schlapkohl, Mary	University of Iowa Hospitals and Clinics
Schneider, Jo	Naval Medical Center – San Diego
Scott, Tamara	Kaiser Permanente – Oakland
Scott, Tammy	Johns Hopkins University
Senn, Stacy	Children's Healthcare of Atlanta – Egleston
Sennett, Margaret	University of Virginia
Sepanak, Michelle	Hurley Medical Center
Seward, Dawn	Nemours Childrens Clinic – Orlando
Shepperd, Barbara	Children's Hospital Colorado
Shimmel, Cathy	Winthrop University Hospital
Shockey, Debra	Virginia Commonwealth University
Simon, Pam	Lucile Packard Children's Hospital, Stanford University
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Sleeper, Kimberly	Dartmouth Hitchcock Medical Center
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Sneidman, Rebecca	Geisinger Medical Center
Sonneblick, Betsy	Saint Joseph's Regional Medical Center
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Spencer, Brooke	Royal Childrens Hospital – Brisbane
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Tracey, Lana	Alberta Children's Hospital
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Tracy, Ellen	Children's Hospital of Philadelphia
Turpin, Kate	Women's and Children's Hospital – Adelaide
Vega, Jennifer	Lee Memorial Health System
Vertz, Lori Saint	Vincent Hospital
Vrooman, Patricia	Randall Children's Hospital at Legacy Emanuel
Weintraub, Meredith	Children's Hospital of Alabama
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Woo, Kathy	Mattel Children's Hospital UCLA
Yun, Christine	Miller Children's Hospital
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 Saint Christopher's Hospital for Children
 Rainbow Babies and Childrens Hospital
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 Yale University
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 Memorial Regional Hospital/Joe DiMaggio Children's Hospital
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 San Jorge Children's Hospital
 East Carolina University
 Tulane University Health Sciences Center
 M D Anderson Cancer Center
 Santa Barbara Cottage Hospital
 University of South Alabama
 Children's Hospital of Eastern Ontario
 Cardinal Glennon Children's Medical Center
 T C Thompson Children's Hospital
 Wayne State University
 Scott and White Memorial Hospital
 University of Missouri – Columbia

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