

aphon

## 40 Years of Building a Legacy

Reflections on Our History and Lessons for Our Future

Edited by Kathy Ruccione, PhD MPH RN CPON® FAAN

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## Introduction

APHON is celebrating its 40th anniversary this year—what an achievement! To think, APHON originated from an impromptu meeting back in 1973 when four pediatric oncology nurses got together and shared practice problems and successes, knowledge, and mutual support. We officially reached incorporation status in 1976. Today, 40 years later, we're stronger than ever with almost 3,700 pediatric hematology/oncology nurses sharing best practices and supporting one another worldwide.

Throughout the year we have been marking our anniversary in different ways—through social media, at the annual conferences in Indianapolis and Palm Springs, and through blog posts shared on the APHON Member Connection. Members have been posting about aspects of APHON over the years, including the evolution of APHON's local chapters, annual conferences, *JOPON*, international outreach, advocacy, to name some of the topics.

Ours is a remarkable story of resilience, accomplishment, setbacks, friendship, and lifelong learning. The blog posts are not in any sense a systematic review or an impartial recounting of facts. They are filled with the perspectives and the voices of our colleagues, all contributing to the lively mosaic that is APHON. I hope you will enjoy them and consider going to the Member Connection and commenting on them or adding your own perspective, memories of the past, and hopes and visions for our future. After all, APHON is who we are.

With warmest regards,

Kathy Ruccione, PhD MPH RN CPON® FAAN

APHON President

Editor, APHON: 40 Years of Building a Legacy

# APHON's Growth and Development

Casey Hooke, PhD APRN PCNS CPON®



I have a fascination with the wonder of growth and development. I think it is vital as pediatric hematology/oncology nurses that we are attuned to the developmental work that needs to be accomplished in childhood, whether the child has cancer or a blood disorder or is healthy. As I tell anyone who will listen: there are no “time outs” in development, so we need to support children in being successful in the work of childhood if we want them to become healthy adults.

Thinking about APHON's 40<sup>th</sup> birthday, I considered some of the developmental theorists to see how our “age” fits with theory. According to Erikson, APHON should have reached “generativity,” meaning that we are contributing to the world. Check that box off. Just look at the output of our members, the quality of our conference presentations, journal, publications including our textbook, core curriculum, chemotherapy/biotherapy manual, patient education materials. We are the “go to” group for expertise and standards of care in pediatric hematology/oncology nursing and our organization rises to every occasion and challenge put before it. It's more difficult to apply the work of other developmental theorists to our

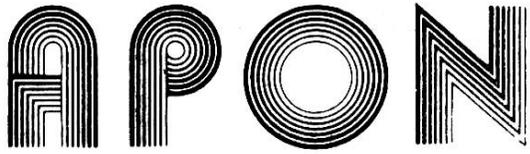
organization (Freud... I'm not going there; Piaget... focused on children's cognitive development; Kohlberg... hmm... I do think our moral thinking is abstract and advanced as reflected in our professional behavior).

So how has APHON evolved into being a productive, dynamic, organization that has successfully reached adulthood? We had a strong core of founding members who did the developmental work of childhood for us. They worked hard and believed in APHON's purpose and mission. I joined APHON in the late 1980s when APHON was in its adolescence, growing and establishing its identity. It became my professional peer group, and the friendships and relationships forged through APHON continue to be the most significant of my professional life. In APHON's late adolescence and early adulthood, certification of the specialty became a reality, the first core curriculum was published, and conference attendance grew consistently. In adulthood, we were secure enough in our identity to expand our focus to include pediatric hematology nurses in our specialty. APHON established the chemotherapy/biotherapy provider program, developed APHON's foundations course, and continued to grow its membership and conference.

To some APHON members, a 40<sup>th</sup> birthday may seem like middle age. To someone like myself, who has been a nurse for 40 years, I think APHON is just getting started and has the energy to rise to even greater heights. We have all the signs of being a vibrant, mature organization. We have new members bringing in their ideas, vision, and youth that is as essential as the wisdom of our more senior members. One of my favorite experiences at conference is to go to a concurrent session and hear a presentation from a young APHON member I know nothing about. I will be blown away by their professionalism, knowledge, and enthusiasm. Then, I will think to myself: yes, APHON is growing and maturing, it is avoiding stagnation and self-absorption (Erikson's dark side of middle age), and our future is bright. Happy birthday, APHON, and many more!

# Reflections on APHON's Beginnings

Gen Foley, MSN RN



When I was interviewed for an article in *JOPON* in 1997 (Ruccione & Hinds, 1997), I was asked about being present as our specialty and APHON were developing. My response was that “I went to a meeting in Boston and met Trish (Greene), Andy (Wood), Shirley (Stagner), Dianne (Fochtman), and (I think probably) Lorraine Bivlack and June McCalla. It was the first time I met people I had only heard about and the thing that impressed me was how generous they were, how willing to share. Andy and Shirley were from St Jude Children’s Research Hospital, which everybody knew was doing such important work with the leukemia kids in particular. They freely shared their knowledge and respected my clinical wisdom. They listened as I talked to them about how we had set up our system of care and they treated me like a peer, which was a really wonderful thing, because I think we were (everybody was) in awe of Trish, Andy, and Shirley. They were people who were in there from the ground up. There was a feeling of camaraderie that we all had something we could share with each other, whether we came from a big place or a small place, whether we had been in it for 15 years or 5, and that we had practice wisdom. The other thing that became apparent was that the standards of care were so uneven across the country. There was a recognition that we needed to disseminate the information we had. It wasn’t perfect; there was a lot we didn’t know and much of it was not based in research. It was experiential, but it was the best we had and we needed to help people not reinvent the wheel or spend time looking for resources that we already knew about. It was a kind of an incredible shared vision.”

I served as APON’s third President from 1977-1978 while in a clinical nurse specialist role at the Massachusetts General Hospital in Boston. It was a tumultuous year for me on many fronts. That winter was record breaking in Boston with over a hundred inches of snow.

During one storm I was stranded at the hospital for 4 days until a National Guard truck took me home. I was the nurse in the Chad Green case and was involved with the courts and the media. My family constellation changed with the birth of my nephew, the first baby in the family for many years.

My life and work provided the background for my presidency. Under the leadership of APON’s first president, my friend Trish Greene, APON was founded in 1974. Incorporation followed in 1976 during Andi Wood’s term by then Parliamentarian Shirley Stagner. (For additional historical information see Greene, 1985 and Foley & Ferguson, 2011). It was my responsibility, along with the Board, to begin to move the organization into the next phase of development. I believe there were 3 important events that year. The first was my signing a contract with Little, Brown and Company for a textbook of pediatric oncology nursing, the teal version of the “Purple Book.” The second was opening a dialogue with the American Nurses Association about national standards. The third was the significant challenge of retaining independence. During my tenure the difficulties of our noble enterprise were becoming clearer. Peds oncology was a small practice area, and we struggled to attain a membership of 100. Finances were a serious problem. Most Board members and committee chairs paid their own expenses without any hope of reimbursement. Joining forces with the Oncology Nursing Society (ONS) was a reasonable path to investigate so I met with the ONS President at the time to discuss options. In the end the Board chose to remain independent, a terrifying decision in some respects, a hopeful, visionary decision in others. We felt that the importance of APON’s mission necessitated independence—a conclusion I believe is now supported by history.

Looking back at that time I realize that another major accomplishment was extending the peer support network. Nurses in smaller programs still experienced loneliness and isolation, but as APON grew those feelings diminished. Thanks to the generosity of time and talent

of the early membership, support networks formed and life-long friendships developed.

An important factor was pride in our work and a commitment to raise the standards of care throughout the country for the kids and their families. Peds oncology has

always been a demanding career choice, a vocation, not a mushy, sentimental road. APON's early years set the tradition of vision, courage, and determination that exists even as we celebrate 40 years!

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## 40 years of APHON Conferences

Melody Watral, MSN RN CPNP-PC CPON®

As we approach this remarkable milestone in our organization's history, I was asked to think back on the first time I attended an APHON Conference and what has kept me coming back for "so many years." Reviewing the APON/APHON Conference list, it appears that I have managed to attend for 19 of the last 25 years. Guess that makes me a "regular." Here are some of my reflections back on several of the APHON Conferences I've attended:

**Boston, 1991:** My first APON Conference. I traveled with several of the other nurses I worked with at that time to see what the APON Conference was all about. Strong memories of being in awe of the "leaders in Pediatric Oncology Nursing" who were in attendance. Everyone was so friendly – it didn't matter if you were a newcomer or a legend, everyone was talking with everyone. The exchange of ideas and experiences certainly piqued my interest. Touring Boston was fun, too!

**Minneapolis, 1992:** The CPON test pilot was offered prior to the start of conference. Seemed like the room was packed with pediatric oncology nurses wanting to assist in setting the test standards for certification. Everyone was talking about the test and anticipating the real-thing the following year. Conference was great. Went to a NORSTARS Hockey game while everyone else was shopping at the "Mall of America."

**Reno, 1993:** The first CPON Exam! Seemed like everyone was a nervous wreck prior to the test. We all survived and most of us passed. I was so proud to be able to add CPON® to my credentials. Conference was a blur – wondered if the casino atmosphere contributed? APON's President sat down next to me at the slot machines – she won \$100 off the bat, took her winnings, and never looked back (talk about self-control!)

**New Orleans, 1998:** Conference was memorable in so many ways. We went on a preconference Bayou Tour in the pouring rain – and threw marshmallows to feed the alligators! Tropical Storm Frances affected travel to New Orleans for many participants and speakers. Wading through the water on Canal Street was an experience. My group headed over to Pat O'Brien's for a round of Hurricanes after the conference (it figures that the sun came out just as Conference was concluding).

**Portland, 2005:** Walking in the Portland Rose Garden with Kathy Ruccione prior to the conference was a turning point for me. During our conversations, Kathy's easy

manner and supportive nature made the idea of contributing to APON in a leadership capacity plausible for me.

**Hartford, 2006:** A major change happened at this conference, recognizing that many of us specialize in taking care of patients with hematology diagnoses. This is where APON became APHON!

**Albuquerque, 2008:** Joetta Wallace had called me the year prior, offering me an "APHON Opportunity." I accepted the Chair Position for the Albuquerque Conference Planning Committee. The Committee Members were so dedicated to maintaining the HIGH standards of all the previous committees and they did an incredible job. I will remember 2008 fondly as the year that the "Ribbon Wars" unofficially began....

In 2010, the membership elected me to the APHON Board as President-Elect!!! The idea that so many people had that kind of faith in my ability to serve them on the Board was mind-blowing. Dave Bergeson and Nicole Wallace guided me through the initial choppy waters into the steady stream of activity that flows through your Presidency. I even got to chat about 'TWD' with Nicole! The year sped by and then I was in Pittsburgh and Louisville as your President! I do believe that I tried to give away a \$100,000 award at one point – needless to say, everyone had a laugh about that one. Good thing that Jami Gattuso came along to keep things on an even keel.

Attending the annual APON/APHON Conference is one of the highlights of my "professional year." A truly safe, nurturing environment, both personally and professionally. I've been lucky enough to have made lots of friends and been mentored by a group of fellow APHON-ites that I look forward to seeing and working with year after year. These people – and you know who you are – have seen me through some incredible times.

Learning, innovating and growing – that's what keeps me and so many other people returning to the APHON Conference year after year.

## APHON: 40 years of Nursing Education

Susie Burke, MA RN CPNP CPHON®

Nursing education always has been – and remains – a key component of APHON’s mission, beginning in the 1970s with informal gatherings of a few nurses who met to share their experiential knowledge and discuss ways to standardize care. This deep tradition of collaboration for education has carried forth to our current discussions as we gather together at conferences, during conference calls, through committee work, and at the bedside to outline what hematology/oncology nursing care looks like today.

One of the highlights of my educational calendar is the Annual Conference, and I know this is something that many of us look forward to each year. Whether you are a first-time participant or have been to many conferences in the past, there is always something for everyone. Attending Conference provides an opportunity to advance our knowledge and skill, network with colleagues and old friends, establish new connections, become a collective voice on topics that we are so passionate about, and hopefully provide some self-care as we take time to nurture our inner spirit.

The first Annual Conference was held in Bethesda, Maryland, in 1976 with a theme of “Accepting the Challenge of Pediatric Oncology.” Our early conferences were held in conjunction with other meetings, but in 1979 APHON hosted its first independent conference in Chicago. As I browsed through the APHON conference titles, I saw many similarities in themes over the years – some of the words that were used were *challenges, current issues, advancements, reflection, progress, diversity and collaboration*. As we strive to advance the field of pediatric hematology/oncology nursing, many of these same words are echoed today, a thread connecting our past to our future.

Those who presented at some of the early APHON conferences will recall the use of overhead transparencies and 35mm slides. Back then, our worst nightmare was having the projector bulb burn out in the middle of a presentation or dropping the slide carousel as you walked to the podium. One APHON presenter recalls the slide carousel catching on fire at the Annual Conference

in Miami, and literally watching her presentation go up in flames. With advances in technology, PowerPoint presentations have replaced overheads and slides, and we now have the technological sophistication to animate our presentations, insert videos as well as interactive imaging, upload our handouts remotely, and carry our entire presentation on a flash drive. It makes packing for Conference so much easier.

Advancements in technology opened up other new opportunities. Recognizing that there were many members who wanted to remain current in their knowledge although they were unable to travel to the Annual Conference, APHON began offering Web-based learning opportunities in 2010. We now offer six webinars per year. Journal articles have also provided an opportunity for nurses to advance their knowledge and earn CEUs. These initiatives have expanded our capabilities to reach and teach pediatric hematology/oncology nurses across the globe.

During her APHON Presidency, Rita Secola identified a need for leadership development and in 2006, the pre-conference leadership workshop was started. I have had the opportunity to attend a number of these workshops. They always offer a great deal of food for thought, practical knowledge, and “take away’s” that have been quick wins at the office, while providing a great deal of humor and entertainment.

In 2010, during Joetta Wallace’s Presidency, APHON and COG nurse leaders agreed to offer a COG track during the APHON Annual Conference. The COG track provides us with increased awareness of open clinical trials, research updates from recent clinical trials, and education on newer innovative therapies, as well as nursing roles/responsibilities in clinical trials. With the recent explosion of immunologic and biologic therapies, I have personally found these sessions to be quite beneficial in my clinical practice. This educational initiative demonstrates the value of collaboration between the COG Nursing Discipline and APHON that benefits members of both organizations.

APHON launched the Pediatric Chemotherapy/Biotherapy Provider Program in 2006, and since that time, we have trained over 30,000 registered nurses; we now have instructors in the United States as well as internationally. This course quickly became the foundation for chemotherapy and biotherapy education throughout most pediatric oncology programs and has even become one of the standards by which the *US News and World Report* measures their top children's cancer centers.

APHON has a longstanding commitment to providing quality education. Since 2008, our continuing education programs have been accredited through the American Nurses' Credentialing Center (ANCC). During my recent term as APHON's Education Provider Unit chair, I had the opportunity to highlight APHON's educational programming through the ANCC reaccreditation process. It was a rigorous and lengthy process based on our educational

design backbone with a focus on key education standards outlined by ANCC. Some would consider the reaccreditation brutal (admittedly, I did at times), but what I realized was that this process allows APHON an opportunity to shine – to share with others who we are, what we do, what we stand for, and what we have to offer. Through this process we were able to confirm that we continue to provide quality outcome-based education with the sole purpose of improving, enhancing, and advancing care to children, adolescents and young adults with cancer and blood disorders.

As I reflect on APHON's 40-year legacy of education, and our outlook for the education of future pediatric hematology/oncology nurses, I think of the words of Nelson Mandela: "*Education is the most powerful weapon we can use to change the world.*"

## The Evolution of APHON's Patient/Family Education Resources

Ellen Olson, MS RN CPNP BMTCN CPHON®

I was first introduced to APON when the organization was only two years old and I started working at the Pediatric Oncology Branch of the National Institutes of Health with June McCalla, who was one of the original members of APON. The core purpose of APON from the beginning was to educate, including patients and families. In the early days of APON, patient/family education material looked much different than the publications and various resources we now provide for patients and families. There was no management association involved in the organization yet, and patient/family education materials were not professionally published. A core group of nurses developed information sheets on diseases and chemotherapy. Information on various drugs or diseases was typed, copies were made, and usually there were no pictures or illustrations. For years I kept copies of these information sheets in my APON file, but when I went to look for them in my file as I was writing this blog they were no longer there.

What I did find was my copy of the first edition of the “purple book,” *Nursing Care of Children with Cancer*. When it was initially published in 1982, it was blue! This book addressed many of the learning principles that provide the foundation for teaching patients and families about cancer treatment. Since this first edition there have been three more editions that further addressed the education needs of our patients and families. Publications from the first 20 years of APHON are shown in the Table reprinted from a 1996 JOPON article by Sue Heiney and Fran Wiley.

In my file I also found a publication by APON called *Cancer Chemotherapy Handbook* (2<sup>nd</sup> edition), which was published in 1990. At this point APON was working with a management association to help publish educational materials. This book was preceded in 1978 by APON's publication of a handbook of cancer chemotherapy; another edition was published by APON in 1985. These books were the stepping stones to patient/family education because they educated the nurse on the chemotherapy and special nursing care for children receiving

chemotherapy including family teaching on administration of home chemotherapy.

In the early days of APON there was a committee structure that worked with clinical practice, research, and educational aspects of pediatric oncology nursing. It was the patient/family education committee that collaborated to further develop educational materials to help families understand their child's disease and treatment. Slowly through the years, the early APON handouts evolved into the Pediatric Tumor Series that include Handbooks for Families and the Cancer Treatment Fact sheets, which could be purchased from APON and given to families around the time of diagnosis. There were initially five handbooks that focused on the Ewing sarcoma family of tumors, neuroblastoma, osteosarcoma, rhabdomyosarcoma, and Wilms tumor. The Cancer Treatment Fact Sheets, initially only available in English, were translated into Spanish when the second edition was published. Following the basic principles of starting education early and using multiple forms of education including written and audiovisual aids to facilitate comprehension, a slide orientation program – later converted to a PowerPoint presentation – called “When Your Child has Cancer” was added as a resource.

Based on the needs assessment of the organization at a strategic planning meeting in the early 2000s APON's committee structure was transitioned to the Steering Council. The Steering Council purpose was to engage members in individual projects that could be completed rather than being involved in all the projects of an entire committee. Many more patient/family education handbooks were added to the initial tumor handbook series, starting with CNS tumors and then adding retinoblastoma, germ cell tumors, ALL, AML, rare tumors, Hodgkin lymphoma, and nonHodgkin lymphoma.

In 2006, to acknowledge that most members cared for hematology as well as oncology patients, the membership voted to become APHON. APHON also expanded the definition of the scope of hematology/oncology nursing care to include adolescents and young adults. With this

expansion the patient family/education library of materials and media was expanded. Now the patient education handbook series includes ITP, aplastic anemia, hemophagocytic lymphohistiocytosis (HLH), Langerhans cell histiocytosis (LCH), radiation therapy, sickle cell disease, thalassemia, hemophilia, and fertility preservation. As technology has evolved so has patient family

education. Through the years APHON's educational materials have transitioned from being paper documents sent through the mail to having many available as PDFs that are downloadable from the APHON website.

It will be interesting to see how patient/family education materials evolve in the next 40 years!

**TABLE 4.**  
**Publications**

Date	Name	Author/Editor
1974	Newsletter	Trish Greene, President
1978	Cancer Chemotherapy: Theoretical Concepts and Nursing Implications	June McCalla, Rick Davis, Consulting Pharmacists, NIH
1979	Standards of Care	Genevieve Foley (published by ANA)
1981	Bibliography for Pediatric Oncology Nurses (also published 1981, 1982, 1983)	Dianne Fochtman
1982	Nursing Care of the Child With Cancer	Gen Foley and Dianne Fochtman
1984	Journal of the Association of Pediatric Oncology Nurses (JAPON)	Dianne Fochtman, Editor Patti Liebhauser, Assistant Editor
1985	Cancer Chemotherapy Booklet (ed 2)*	Mary Waskerwitz, Nancy Brown, and Robin Kramer
1986	Continuing Professional Education Course	Components written by APON members
1987	Scope of Practice and Outcome Standards of Practice for Pediatric Oncology Nursing	Georgina Bru
1988-1989	Speakers and Consultants List	Myra Antill-Woolery
1989	Journal title changed to <i>Journal of Pediatric Oncology Nurses</i> , (JOPON), and published by W.B. Saunders	—
1989	Patient Family Annotated Bibliography	Kathy Ruccionne, Robin Kramer
1990	Cancer Chemotherapy Handbook (ed 3)	Terry Robinson, et al†
1991	Membership Directory	Not Applicable
1992	Patient/Family Education Resources	Patient/Family Education Subcommittee
1992	Chemotherapy Update	Terry Robinson, et al†
1992	Biotherapy: The Fourth Modality of Cancer Treatment	Rita Secola, et al†
1993	Patient/Family Education Resources	Patient/Family Education Subcommittee
1993	Nursing Care of the Child With Cancer (ed 2)	Gen Foley, Dianne Fochtman, Kathi Mooney
1993	Biologic Response Modifier Update	Rita Secola, et al†
1993	Chemotherapy Drug Update	Bonnie Minter, et al†
1993	Pediatric Oncology Study Guide	Cheryl Panzarella, et al†

\*Funding received from Amy Lynn and Ida K. Silverman Foundation to assist in publication.

†Linda Wofford served as managing editor.

Heiney, S., & Wiley, F. (1996). Historical beginnings of a professional nursing organization dedicated to the care of children and adolescents with cancer and their families: The Association of Pediatric Oncology Nursing from 1974-1993. *Journal of Pediatric Oncology Nursing*, 13(4): 196-203.

## Reflections About *JOPON's* Evolution

Kristin Stegenga, PhD RN CPON®



APHON's 40<sup>th</sup> anniversary has given me the opportunity to reflect and share a bit with my fellow members about how the *Journal of Pediatric Oncology Nursing* came to be. Ours is a pretty young specialty. It wasn't until the early 80s that Dianne Fochtman bravely stepped up as our founding editor. That wasn't so very long ago, and yet, all of the correspondence for the journal occurred via mail (the kind you send in the mailbox...). So you, as an author, would mail your manuscript to Dianne. She would read it and then send it out for review (another mailing...) and then the reviewers would mail it back to her...and then she would mail it back to the author for revisions and then the process would start over again until the manuscript was ready for publication. It is hard to imagine now in this era of instant gratification!

One of the many things that was fun to hear from Dianne was how much she enjoyed working with authors. For her as an editor, it was most gratifying to see an author through the process and see the changes in both

manuscript and person! That is certainly one of my favorite aspects of this role as well! Although I will tell you a funny story about Dianne and Cindy Stutzer, our awesome Assistant Editor. Cindy submitted a VERY LONG manuscript (urban legend has it at 50 pages, but I think that *might* be an exaggeration!) to Dianne and was told that it was indeed a very good manuscript BUT it would need to be "cut down." Each word in this manuscript was precious to Cindy, as it was the product of her master's project...she was unsure that there was a single word that could possibly be let go! In her wisdom, Dianne worked through that process with Cindy and not only was the manuscript shaped to a manageable and publishable length, but Cindy learned some of the wonderful lessons she shares with authors today in her role as Assistant Editor!

Pam Hinds was our second editor, assuming the reins from Dianne in 1994. During this time, the focus of the journal turned to research and an ethics column was added. There was remarkable reaction to an editorial she wrote entitled "Pass Me the Blue" (Hinds, 1994) about caring for a young girl who ultimately died from her cancer. This editorial resonated so strongly with readers that Pam received calls and letters to the editor. It was an unexpected and wonderful opportunity to connect with like-minded people seeking to provide the highest quality patient care and recognize the importance of our connection with our patients. So much of what we do is about connections, with each other, with our co-workers, and, most importantly, with our patients.

In April 1998, Nancy Kline became our third editor. She shepherded the journal through the evaluation process so that *JOPON* could join the journals receiving an Impact Factor\* each year. This was a huge accomplishment for us as a specialty and as a journal! It was fun for me to look back through the journals from Nancy's time as editor and see the evolution of *JOPON* under her tutelage. I mentioned the mailed submissions early in the process. In 2002, there are published instructions on how to submit a disc with your manuscript on it. I must admit

I didn't ask anyone what came in between, but as I look at the relative ease of our computer system, even with its quirks, I am thankful to be the editor now!

Nancy was a cheerleader for all! She was always listening for new ideas and encouraging people to write. She would hear someone talking about something they were doing and encourage them to write about it. Some weren't sure if it was a blessing or a curse to catch Nancy's eye or ear with their work or idea since she also had a great memory. Under her guidance, however, many people became published authors. She made it all seem possible for people, and that is a tremendous gift. Nancy left us all prematurely (at least that is how it feels to us) almost exactly a year ago now (at the time I write this). She wrote one of her editorials noting that patients had left the earth before she was ready and far too early and then she did the same! I imagine the reunion was fun! Perhaps a bit like camp...which was Nancy's other love besides being the best editor she could be for *JOPON*.

Cindy Stutzer joined *JOPON* as assistant editor, working with Nancy in 2001, after serving on the Editorial

Board under Pam. She is flexible and funny, nurturing, and precise. These are such perfect qualities for her role! And for a friend, by the way. I highly recommend her for both! Losing Nancy solidified both our partnership in *JOPON* and a rock solid, if hilariously irreverent friendship!

So that brings us to now. I am *JOPON*'s fourth editor – just the fourth in almost 40 years...WOW! And look at the shoes I have to fill. When I was little, I couldn't wait to fit into my mother's shoes! You know what?!?! I NEVER did! Seriously! Stopped growing! But as I look at the legacy of these fine nurses who have come before me and I think of the qualities they have brought to the journal and the editorship—strength, vision, enthusiasm, nurturing, flexibility, and passion for writers and their writing—I know I share many of these qualities and strive for all of them! Together, we will continue to grow *JOPON* just like *APHON* for another 40 years and beyond!

*\* The journal Impact Factor is the average number of times articles from the journal published in the past two years have been cited in a given Journal Citation Reports year.*

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## APHON Counts' Growth and Development: 40 Years Later.

Kaye Schmidt, MA RN CPON® NEA-BC; Editor *APHON Counts*



*APHON Counts* has come a long way in 40 years! When I was asked to write this blog, I thought that although I am the current editor, I am not old enough to know the 40-year history of *APHON Counts*! But then I started digging (with the help of the national office and some fellow APHON colleagues), and sadly, I was the one that came up with copies of the oldest *APON Counts* that any of us could find! The oldest copy I found was from January 1994, and it was listed as Volume 8, Number 1. That would suggest that *APON Counts* may have originated in 1987! It also suggests that I am not as young as I think, and perhaps I am a bit of a pack rat!! And yes....I was a pediatric hem-onc nurse in 1987!!

The 1994 newsletter that I found was a 16-page newsletter, with highlights from the previous conference, several individual APON member highlights on recent accomplishments, and a column on certification in which the first CPON pioneers were highlighted! The article highlighted a 69% pass rate for the first 451 nurses that had taken the new CPON exam, introducing the first 309 nurses who had passed the CPON pioneer exam! There was also a small column on President Bill Clinton's 6 principles of Health Care Reform. How amazing that, 22 years later, health care reform is still largely on our minds, and former President Clinton's wife and former First Lady Hillary Clinton is most likely going to be the Democratic nominee for President later this year! The Editor of this 1994 newsletter was Judy Rollins, from Rollins & Associates, suggesting that APON was using an external organization to edit the newsletter. Fast forward to 2016 and

our own membership writes and edits the 20-24 page *APHON Counts* quarterly newsletter! Beginning in 2001, it appears that Angela Ethier was the first Editor from our membership. Following her were Mary Nelson, Karla Wilson, Sharon Bergeron, and myself.

The 1996 *APON Counts* newsletter suggests that a new APON logo was selected that year, in honor of the 20<sup>th</sup> anniversary of APON. Our 20<sup>th</sup> anniversary was celebrated at the annual conference in Seattle. APON was emerging from a financial crisis at that time, having been the victim of embezzlement of almost \$300,000 the previous year. The Spring 1997 *APON counts* headline stated "Blue Skies Ahead as APON Finances Return to Black Ink."

*APON Counts* started adding regular columns in 2003. It was then that regular columns such as the Practice Corner, Local Chapter News, and News on Certification began emerging.

The Fall 2006 *APON Counts* headlines are "APON Becomes APHON to Begin its Second 30 Years!" The Winter, 2006-07 newsletter was the first one titled "*APHON Counts*," signaling the official addition of the hematology population to the organizational mission.

Fast forward 10 more years, and we have so much for which to be thankful. APHON is financially strong. Our membership has grown tremendously. *APHON Counts* is now a quarterly newsletter devoted primarily to educational information and ongoing learning for the membership. Each newsletter has 11 columns, as well as the editor's introduction, a list of current educational opportunities and association news. A theme is chosen for

each newsletter so that the columns in each newsletter are all focused on a current issue of widespread interest to the membership. The newsletter is written by members from all around the country, and we pay close attention to obtaining columns from multiple centers, hoping for representation of pediatric hem-onc centers across the membership in the U.S., Canada and other participating centers around the world.

As I think back to the newsletters that I can find from as early as 1994, we were completely dependent on the U.S. mail for this type of information! We still mail the hard copy of the newsletter today, but all members have the ability to go the APHON website now and can find copies of the *APHON Counts* newsletter for the last 10 years (back to 2006) online!

*APHON Counts* is a great opportunity for young/new authors to try out their publication skills. “My Most Memorable Case” is a column where a nurse may share a case that has had a significant impact on their career and/or on them personally as a nurse. Anyone who is interested in writing for *APHON Counts* is encouraged to fill out a “Willingness to Serve” form or to contact the editor directly ([kaye.schmidt@childrens.com](mailto:kaye.schmidt@childrens.com))! The themes for the year are determined at the annual conference each year and are included on page 2 of the newsletter for the year. We are always looking for new authors and this is a great opportunity to get involved in APHON!

## The Transformation of APHON Local Chapters

Janice Nuuhiwa, MSN RN APN CNS CPHON®



This is my task at hand: write a blog about the local chapters—in 800 words. It seems like too many and not enough all at the same time.

This might sound like a cliché, but the local chapters have a special place in my APHON heart. In 2001, the Chicago chapter of APON (before the “H”) was my introduction to this community of advocates, the beginnings of my leadership adventures, and the foundation for building a network of extremely talented professionals and friends. I am beyond amazed at the professional development opportunities I have had within the structure of the local chapter and the Local Chapter Committee. I often wonder if those who gathered together 40 years ago envisioned what we look like today: how many APHON members, associate members, students, and guests would meet, as a chapter, in various cities sprinkled across North America. I wonder if they imagined the work that would be done within the local chapter structure: all the educational sessions, local/regional conferences, chemo/bio courses, fundraising, community service,

recognition and FUN. I’m sure they knew about all the fun we would have. We are, after all, pediatric nurses.

And as pediatric nurses, we are well versed in growth and development. And grow and develop is what we did! While APON was incorporated in 1976, the very first chapter formed (SCAPHON) was incorporated in 1982. One of SCAPHON’s founding members became the local chapter committee chair and now serves as APHON President: Kathy Ruccione. In 1989, a chapter growth spurt occurred as 14 local chapters became incorporated. Then, 22 chapters were added in the ‘90s. The Northwest chapter was the only chapter to brave the unknown that the year 2000 would bring and was chartered in Y2K. Subsequently, 14 chapters were chartered in the first decade of the new millennium and 11 more in the past decade, with the Lexington chapter being the most recent. Throughout the years, the number of local chapters ebbed and flowed, but the core purpose—to support and advance nurses and their practice in order to optimize outcomes for children, adolescents, and young adults with cancer and blood disorders and their families—remained

constant. A lot of good work has been done through the local chapters. Much of that is unknown to the membership at large but held dear by the patients and families who reaped the benefits from nurses participating in local chapter activities, from cooking dinner at the Ronald McDonald House for weary families to the distribution of special beads from the Beads of Courage program and everything in-between. My, we were a busy bunch!

And busy, we've stayed. In 1992, APON had to transition the local chapter oral reports from the general membership meeting to the Local Chapter Committee meeting in addition to providing a brief overview in the APON Newsletter because of the sheer number of local chapters. From paper newsletters and meeting flyers distributed via snail mail to websites, Facebook pages and the APHON Member Connection, the local chapters currently leverage technology to connect with their members. And the local chapters have much to offer. Several chapters provide educational meetings beyond what is required. Educational topics are as diverse as the chapters themselves, including engaging industry to provide education and integrating multidisciplinary team members to present their topics of expertise. Others offer a plethora of community service events, such as partnering with local and national philanthropic organizations, conducting celebration picnics, providing survivor scholarships, and supporting camp initiatives. Creativity continues to shine through as local chapters hold fundraisers to support their service projects and even assist their local chapter members. The Greater Philadelphia Area Chapter created the \$0.35/day campaign in order to encourage members to collect their pocket change in an APHON Mason jar as a way to prepare for paying their national dues. All of these amazing opportunities afford

both the novice and expert nurse the opportunity to further their personal professional development by being engaged in chapter activities. From organizing educational meetings and events to participating in the planning of a national conference (I love seeing the host city or state chapter at conference), chapter leadership skills flourish, which leads to future opportunities. Think about a few of the past local chapter chairs: Casey Hooke, Roseann Tucci, Angela Either, Beth Siever, Cheryl Rodgers—leaders who have made an impression upon our professional organization, in part due to their involvement with their local chapter and on up through the Local Chapter Committee.

Eager to step onto the national leadership scene, Beth Siever was the Local Chapter Committee chair who gave me the opportunity to become a (then) local chapter vice chair. I was both thrilled and filled with trepidation at the thought of serving on this committee and overseeing a group of chapters. I was inspired by her passion for our organization. I credit Cheryl Rodgers with the patience to mentor me into being a capable Local Chapter Committee chair as she passed on the proverbial leadership torch, aka the APHON Local Chapter jump drive (loose-leaf binders are no longer needed). I am truly grateful for those experiences. But mostly, I am grateful for the many years I had the privilege of perusing chapter reports, marveling at the activities that the chapters created, hearing the excitement in the voices of founding chapter members as they prepare to charter, reading about all the good work that is being done now, all because a few nurses, 40 years ago said, yes, we should do this. We should be APON!

And so we are. But with an “H”!

Rats, this turned out to be 934 words.

# How Did an “H” Get Into APON? Changing Our Name to APHON

Karla Wilson, MSN RN FNP-C CPON®



As we reflect on the 40 years of our association’s history, many of the “older” members remember when we were APON and “newer” members might not even know that APHON started out as APON. So how did an “H” get into APON, turning us into APHON?

## **In some ways it was because of a letter....**

In the Spring of 2005, Mary Nelson (the editor of *APON Counts* at that time) received a “Letter to the Editor” from Eufemia Jacobs, PhD, RN, an APON member who mainly specialized in pediatric hematology. Eufemia’s letter posed this question:

*“Would APON, JOPON, and APON Counts consider adding hematology to their titles to reflect the work of hematology-oncology nurses, similar to the American Society of Pediatric Hematology/Oncology (ASPHO)?”*

In other words, Eufemia was asking: “Could APON become APHON?”

For several years there had been a great deal of discussion regarding the roles of APON members. It was well known that many members cared for patients with hematological disorders as well as oncology patients. Evaluations at the annual conference were consistently

suggesting hematology issues as part of future topics. Beginning in the late 1990s, based on these requests, the conference program planning committee began adding significantly more hematological topics to the conference agenda. The sessions with hematological topics were found to have very high attendance along with overwhelmingly positive evaluations.

At its 2001 strategic planning meeting, based on this type of input and following much discussion and debate, the APON board changed the association’s mission to read, “APON provides and promotes expertise in pediatric hematology/oncology nursing practice to its members and the public.” The vision statement developed simultaneously stated, “Children and adolescents with cancer and blood disorders and their families will receive the highest quality of care.” The wording for both the Vision and Mission statements was chosen very carefully in order to appropriately reflect the practice of the membership.

In 2004, the APON board reaffirmed the decision to include blood disorders in our mission statement, revising it as follows: “APON provides the leadership and expertise to pediatric hematology/oncology nurses by defining and promoting the highest standards of practice and care to the pediatric and adolescent community.” The existing vision statement was expanded to say: “(APON) provides and promotes expert practice in pediatric hematology/oncology nursing to its members and the public at large.”

A decision was then made to have an annual hematology issue of both *JOPON* and *APON Counts*, and develop “Foundations of Pediatric Hematology Nursing,” as the third in the series of APON’s “Foundations” CD-ROMs (published in 2007).

Following Eufemia’s letter, the APON board decided to survey the membership to see if there indeed was a desire for APON to become APHON. The membership response was overwhelmingly in favor of the name change. Many of the survey respondents’ comments, especially those of bedside and ambulatory care nurses, related

that they had always cared for hematology patients alongside oncology patients and felt they should be recognized as being both a pediatric hematology and oncology nurse.

As you can see, although discussions about including hematology content into our annual conference had been occurring for several years and our Mission and Vision Statements had been revised to include hematology, it was Eufemia's letter that actually provided the impetus for the APON board to give more thought into moving forward in formalizing inclusion of hematology into our professional organization. Therefore, to mark our 30<sup>th</sup> anniversary in 2006, APON officially became APHON with a roll out of our new name and logo at the annual conference.

Once we officially became APHON the question arose—what about certification? Our certification as a Certified Pediatric Oncology Nurse (CPON) did not include hematology content. If we are APHON, shouldn't our certification now include hematology content and recognition? As the APHON board member who was the

liaison to the Oncology Nursing Certification Corporation (ONCC) board, I submitted a request to my fellow ONCC board members to consider expanding CPON to Certified Pediatric Hematology/Oncology Nurse (CPHON). The ONCC board was very favorable to this request and steps were taken to be able to provide CPHON certification. First a role delineation study had to be conducted and from there the development of a test content outline (blueprint) for the certification exam was developed. A test development committee, comprised of both hematology *and* oncology specialists, was organized and an item writing workshop was held. In 2009, the initial CPHON examinations were administered and the first CPHON designations were awarded.

In summary, this evolution of APON to APHON is an example of how APHON listens to members in order to grow and function. Still, our overall goal over these past 40 years has remained constant and that is to continue to provide educational content and mentorship that best meets our members' needs.

# The Journey of Pediatric Hematology Oncology Nursing Certification: From Inception to Current Reality

Casey Hooke, PhD APRN PCNS CPON®; Karla Wilson, MSN RN FNP-C CPON®



There are approximately 2000 certified pediatric hematology oncology nurses (CPHON®) and 1000 certified oncology nurses (CPON®) with 1629 (983 CPHON® and 646 CPON®) of those certified being current APHON members. So the question arises, “*How did we get to having pediatric hematology oncology nurses certified in our profession, and why did we want certification?*”

## From Casey:

“The process for establishing certification for pediatric oncology (and now hematology) nurses began back in the early 1990s. As one of the original certified nurses who took the first test in 1993 in Reno, Nevada, I was enthusiastic about the concept of certification and committed to showing I had the knowledge and skills to be a certified pediatric oncology nurse. However, I didn’t really know much about what it took to develop and maintain a testing system. That changed when, as the Association of Pediatric Oncology Nurse’s (APON) president elect, I was asked to attend the Certification Corporation of Pediatric Oncology Nurses (CCPON) board meetings as a representative to our “sister” organization.

CCPON was incorporated in 1993 as a separate organization from APON, as the “testers” (CCPON) need to be distinctly separate from the “educators” (APON). We knew that certification was important to our specialty and we wanted our members to be able to demonstrate their capabilities through this test. An excellent history of the development of our certification can be found in the publication, *Certification of Pediatric Oncology Nurses: From Roundtable Discussion to Reality*, by Williams, McMahon, Hasenhauer, Pennoyer, and Wilson, in the January 1995 issue of *JOPON*. CCPON contracted with the National League for Nursing (NLN) to guide them in developing and administering the certification exam. What I remember from those early meetings was the rigor that is required by a certification exam. The testing organization must be able to prove that each question is valid and that test is a true measure of the knowledge and skills required by that specialty. The certification board examines every comment written by the test takers and also analyzes trends in correct response rates (i.e., did too many people get a question wrong?). Being part of these meetings gave me new insight into the meticulousness of certification as well as enormous respect for the detail and expertise required for testing. “

## From Karla:

“Like Casey, I did not know of the complexities of test development until 1990 when I became part of the task force that actually became the board of directors for CCPON when it was incorporated. To develop a certification test that is both reliable and valid, it starts with a small group of experts with a variety of roles, educational levels, and geographical diversity to compose a survey to determine what do pediatric oncology nurses do on a daily basis. This type of survey (known as either a role delineation study or job analysis) was sent out to APON membership and from the information obtained lists were developed that described the tasks that nurses did and the knowledge required to perform them. These results were then used to develop the test blueprint, which

provides the foundation for the exam. The next step in the process was to convene a group of people to actually write the test questions. This process again utilizes nurses of all educational levels, practice roles, and geographical regions. The item writers are trained in test question development and are mentored throughout the process. One very important concept that item writers have to grasp is that questions must reflect general practice throughout the country and not be institutional specific. Every test item must be able to be referenced to show why the correct answer (key) is accurate and the incorrect answers (detractors) are plausible but clearly wrong. All items are reviewed by subject matter experts and editors to ensure accuracy of the item as well as appropriate grammar and punctuation. Every item is “pretested” so that a statistical analysis can be done to ensure that they are appropriate items and are accurate. A robust item bank is required to allow multiple test forms as that helps to ensure a secure exam. Role delineation studies are repeated every few years to maintain an exam that continues to meet current practice, but every time a test is administered each item undergoes statistical analysis to make sure it remains an appropriate, current and valid question. When a test form is completed, a “standard setting” committee (again made up of a diverse group of experts) determines the passing score that is required by a minimally competent nurse. So as you can see the development and maintenance of an accurate, valid, and secure test is quite labor intensive and that also translates to an expensive endeavor that is ongoing.

Due to the small number of pediatric oncology nurses it became apparent that CCPON could not generate enough revenue with testing and recertification fees to continue developing and administering certification tests. In 1999 ONCC purchased the Certified Pediatric Oncology Nurse (CPON®) Examination from CCPON and CCPON as a corporation was dissolved. ONCC offered the first CPON® examination in October 1999. In

2010, in accordance with APON becoming the Association of Pediatric Hematology Oncology Nurses (APHON), a role delineation study of pediatric hematology/oncology nursing practice was obtained and ONCC introduced the Certified Pediatric Hematology Oncology Nurse (CPHON®) examination. With the introduction of the CPHON® credential, the CPON® credential was placed into retired status, meaning it could be maintained by nurses who already had that certification through recertification by professional development, but the actual test is no longer offered; so those new to certification will be awarded CPHON®.”

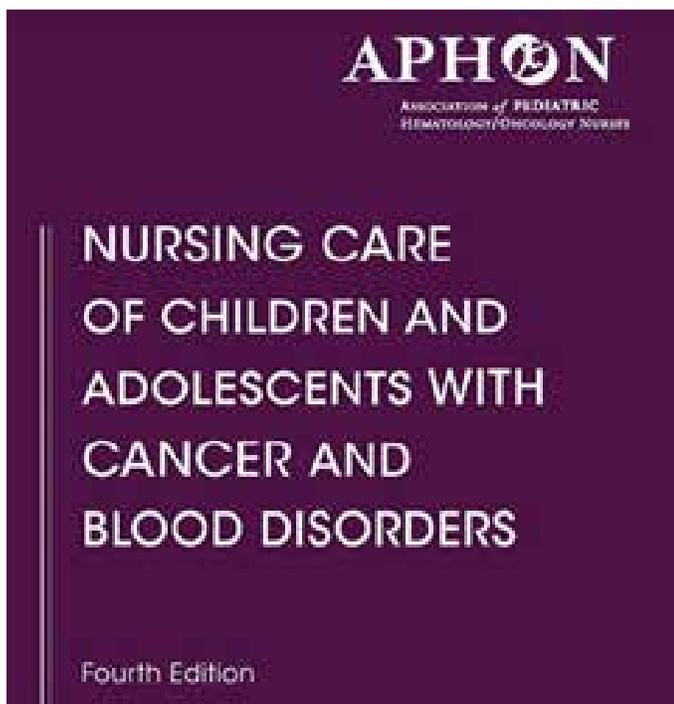
So what is happening with certification now?

ONCC continues to administer CPHON® and is always making changes to stay abreast of current best practices for certification. In 2014 ONCC began offering the Blood & Marrow Transplant Certified Nurse (BMTCN®) for those nurses who specialize in transplant. Currently APHON has 59 members who hold that certification. In 2015, ONCC began year-round testing, reducing the time from applying for certification to the actual test appointment. In 2016, the Individual Learning Needs Assessment (ILNA) process became the primary way to recertify every 4 years. ILNA identifies the nurse’s knowledge strengths and weaknesses allowing the nurse to complete professional development activities that strengthen knowledge.

Just as nurses need to grow and develop and stay abreast of new innovations in practice, the certification process must do the same to ensure that there is meaning and value with the credential that we have worked so hard to achieve. APHON as an organization encourages all members to achieve certification and to be proud of the accomplishments related to certification. Who knew that a simple round table session at the annual APON conference in 1988 would result in over 3000 nurses holding certification in the field of pediatric hematology/oncology in 2017?

## The Story of the Purple Book

Christina Baggott, PhD RN PPCNP-BC CPON®; Dianne Fochtman, PhD RN CHPPN CPNP CPON®; Gen Foley, MSN RN; Katherine Kelly, PhD RN PCNS-BC CPON®



**Gen:** I write this blog as one of two editors who have guided, and written for, all four editions of THE BOOK. Only Dianne Fochtman and I experienced editions one and two, so that time frame is my blog focus.

The Board decision to develop a textbook was bold, ambitious, and a leap of faith. In theory, the idea should never have worked. In the 1970s there were only a handful of APON members who had written for publication. There were no specialty journals devoted to oncology, so members wrote for the American Journal of Nursing, Nursing Clinics of North America, and American Cancer Society meeting proceedings. No one in the group had edited a project of this size. In other words, we had no idea what were getting into; nevertheless, a publisher was secured. Little, Brown and Company was headquartered in Boston. I still remember the day I went to their offices and signed the contract, for by then I was APON's third President. Taking on two enormous responsibilities for which I was not fully prepared was a tribute to my naïveté, faith, and perhaps stupidity.

The responsibility of selecting authors was difficult for me. My clinical setting, the Massachusetts General Hospital, housed the smaller of Harvard's two pediatric

oncology programs. I did not have personal relationships with many potential authors. My friend and mentor, APON's first President, Trish Greene, helped me navigate personnel selection; but it was Dianne who was at a larger program in Chicago and who had been in the field longer than I, who was the essential force. We looked first for clinical expertise, a solid reputation for excellence, then at writing experience. Very few authors had both qualities. We expected mentoring would be a large component of our roles and it was.

Dianne and I agreed that we would read all of the chapters. Word processing was in its infancy and neither the editors nor the authors had access to that technology. I had a conventional typewriter at home with strips of correction tape by its side. Laborious barely begins to describe the process. Content accuracy was critical, but there was no Fact Check, no Google. The MGH library staff and I became fast friends. The medical staff was gracious and helpful, validating information for those clinical conditions I had not encountered.

Ask any contributor to edition one about their most upsetting moment as an author and they will speak of the "Christmas Tree." In order to be helpful and to let authors know which editor made a particular comment or asked a certain question, I wrote in red, and Dianne in green. I was with Trish when her manuscript arrived in the mail. She opened the envelope and in a crestfallen voice announced, "It's a Christmas tree." I wanted to be somewhere else at that moment, but it was good to see her reaction. The colors remained, but the reasons for their use were clarified. So many feelings were hurt inadvertently in the process of making sure that the final product would be clinically correct and well written.

A late surprise came when the cover was sent to Dianne and me. We had no difficulty with the blue/teal color, but the design on the front was not on target. I called it the chaos of cancer, swirls of shapes, out of control. After intense negotiations the cover was changed to an orderly grid of shapes and the book was released for sale.

The second edition found me in New York City at Memorial Sloan-Kettering Cancer Center. By that time I knew many more people and had more resources, one of the most supportive of which was my secretary. In the 10 years since the first edition, peds oncology had experienced an explosion of knowledge, particularly in the sciences. There was a solid underpinning of advances in psychosocial care and a few APON members were involved in nursing research. Dianne and I felt we needed a strong academic partner and so asked Kathi Hardin Mooney to join us. Kathi, a close friend of Trish, was on the University of Utah faculty, and part of a program well known for its strong emphasis on pathophysiology. Kathi had what she called a “scholarship chair” in her dining room. There she piled her academic commitments including her APON chapters. I so admired that she had everything in one place as both my office and home had papers spread out almost everywhere!

For me, there were only a few moments of hilarity with THE BOOK. My favorite story took place in Key Largo, Florida, where Dianne, Kathi, and I had a rare in-person meeting. In those days the editors had to plan to attend the same conference so that our institutions supported our travel. The three of us worked, mostly in the shade, at the beach for two days, then started to go our separate ways. I was the last to leave. I went to my room and found the patio doors wide open, curtains blowing wildly in the breeze. I immediately concluded that there were thieves in the room and they were after my... *manuscripts*. The room was L-shaped with the bathroom at the top of the L and the door to the room at the bottom. I went screaming through the room, opening closet doors until I reached the bathroom where I pulled the shower curtain aside. To my surprise, no one was there! It was only then that I called the front desk. A calm voice instructed me to leave the room at once, that possibly confronting a thief by myself was not a good idea. I haughtily told the clerk that I lived in New York City and that I had already inspected the room. He reached my room in record time, ashen, shaken, and questioning my belief that manuscripts were really that valuable.

The second edition, now 18 chapters long with a beige cover, was published without the cover drama of edition

one. I was very proud of both editions. Each, to me, was a snapshot of where peds oncology nursing was as a profession. I believe Dianne, Kathi, and I carried on the commitment to providing the information needed to ensure safe, effective physical care that rested on a strong scientific foundation. We also retained the focus on the children and teens as developing people influenced by the pediatric and societal issues of their times. We insisted on celebrating our successes, confronting our challenges, and pushing the boundaries of our roles. The book made an enormous difference to moving the specialty forward and I have been blessed to be a part of its history

**Dianne:** I sit here with figuratively “pen in hand.” Actually it’s now the computer keyboard staring at me as I try to recall the adventures of being an editor for the four editions of what was *Nursing Care of the Child With Cancer* on the first edition and became *Nursing Care of Children and Adolescents with Cancer and Blood Disorders* by the fourth edition. I stack the four books up in front of me (I even took a picture, hoping for inspiration) and read what the other editors have written for this blog. Where do I begin? I suppose at the beginning.

The first edition was an adventure into the unknown as Gen Foley describes. The copyright date is 1982, but the work began a long time before that. I am easily distracted from the task at hand and peruse the list of authors, which brings up so many memories. Some have remained friends to this day, some, sadly, have died, and I have lost touch with some. Many have retired (1982 was, after all, 34 years ago) or are no longer in pediatric oncology. That was the edition where my office became a forest of stacks of papers organized by the eight chapters. Editing and checking for accuracy were very labor intensive as Gen describes and we had none of the electronic tools that are now available.

But, perhaps a bit like childbirth, the memories of the birthing of a textbook faded and we embarked on the second edition. The copyright is 1993, eleven years after the first edition came out. We added another editor, Dr. Kathi Hardin Mooney, and increased the number of contributors from 25 to 44. We changed publishers from Little, Brown and Company to W.B. Saunders, changed to a larger size book, increased the chapters from 8 to 18,

and increased the pages from 380 to 533. I was Editor of the *Journal of Pediatric Oncology Nursing* during the time we were preparing the book and also changed jobs from Chicago to Honolulu. Although we had a few more electronic devices, we were still a long way from the electronic age of today and the process remained labor intensive.

The copyright for the third edition (the first purple book) was 2002. This time it only took us 9 years between editions! By that time the field of pediatric oncology had expanded tremendously and new knowledge and the requisite skills were increasing almost on a daily basis. We asked Tina Baggott and Kathy Kelly to join us in this tremendous endeavor. Their talents, relationships, and content expertise greatly expanded our ability to find 67 contributors and include so much important information in the 717 pages. I can remember asking Kathy Kelly how old she was at the time. I'm sure she thought that an odd question, but I needed to know she was much younger than I was and could carry on the commitment to the "purple book."

The fourth edition, a second "purple book," was published by APHON in 2011 with 1184 pages. Once again it was 9 years between editions, but this edition greatly expanded the scope, not only with the addition of hematology, but also with the tremendous increase in oncology knowledge. Imagine coordinating the works of 74 contributors, all knowledgeable but with different writing skills and attention to deadlines, and making it flow well, make sense, and accurately reflect the state of the art. That's what the four of us, Tina, Gen, Kathy and I, accomplished, and still managed to remain friends throughout. Technology certainly facilitated the communication and writing processes, but it was still a lot of hard work. All the work for all the editions is made worthwhile by the knowledge of the children and families who may have been touched, however indirectly, by our work and the nurses who have developed the passion and love for hematology/oncology nursing because of the words we helped to disseminate.

**Kathy:** I remember the dinner in Phoenix when Gen and Dianne invited Tina and me to join them to edit the third edition of the textbook now affectionately known as "the Purple Book." I was so honored to be asked, I said yes

without any true understanding of what I was getting into. We outlined the book at that very meeting and began to recruit authors and potential reviewers for each chapter.

We tore up the fax machines for that edition as we received and forwarded chapters to each other for review. Thank goodness we all had supportive employers! I know that reviewing these chapters and the edits really honed my writing for the future. Seeing how Dianne could take a very convoluted sentence and rearrange a few phrases to produce a very clear and easy to read sentence was almost magical.

Editing a book is A LOT of work. So much so that I thought after it was done – heck, after completing this book, returning to school to complete a PhD would be a piece of cake. Well I was wrong, but I learned so much from being part of this experience that it did make graduate school go a bit smoother.

When we moved into the fourth edition, which was now 35 chapters long, we had access to the Internet!!! Hard to believe that the first three editions were done first by snail mail, then Fed Ex, then fax, and finally a communication format that really facilitated more rapid and easy review across the authors and editors. We also introduced the use of reference management software, which was critical to helping our editing process. Before, if we deleted a sentence with a reference, it meant renumbering everything in the text and reference list. Now EndNote or Reference Manager or Zotero or any of the others does it almost magically. I will not write without a reference manager ever again.

It will be exciting to see what shape the "Purple Book" will take in the future. In this era of evidence based practice and the almost unrelenting publishing of important studies to guide our practice, we will need to carefully think about what kind of reference our membership needs.

The best part of this experience is the wonderful friends Dianne, Gen, Tina, and I have become through the shared work of this book. We've seen each other through marriages, births of several children, grandchildren, nieces and nephews, death of a spouse, three PhDs, job changes, and so much more. What a ride!!

**Tina:** I came on to the project along with Kathy at the third edition. Her words ring true of the incredible undertaking of the assignment, a mission that taught us so much about the intricacy of pediatric hematology/oncology nursing and of interpersonal skills when dealing with an enormous team of authors. We brought a new focus with each edition on which I worked, adolescents in the third edition and hematology in the fourth edition, adding two chapters for a total of 35 chapters. At the time we had to search far and wide to get to know the nurses in hematology who were both content experts and willing to take on the writing. APHON membership numbers have exploded in recent years. I recall when we were planning the celebration of reaching 2000 members, but now membership is nearly 4000. We have a fantastic pool of authors poised to start writing and editing the next

edition. Surely the editing team will need to branch out to experts in the newer immunotherapies.

Yes, technology has revolutionized our communication and writing processes. As APHON looks to the fifth edition, an e-book is becoming a real possibility. Electronic texts will greatly expand our readership. As an active nursing member of the International Society of Paediatric Oncology (SIOP) for many years, I have listened to countless nurses worldwide who would love a copy of the “Purple Book.” However, international shipping is cost-prohibitive as it nearly doubles the cost of the text. I anticipate that we will reach more nurses with an electronic format. An international readership is likely to lead to enhanced opportunities for international collaboration. We have so much to learn from one another. It really does take a village, albeit a global one.

## Evolution of International Outreach

Linda Abromovitz, MSN RN BMTCN®; Julia Challinor, PhD RN; Courtney Sullivan, MSN RN CPNP-AC CPHON®

The APHON International Task Force began working informally in the mid-2000s. Initial members were Jill E. Brace O’Neill, Ayda Nambayan, Christina Baggott, Beth Sievers, Mary Yeane, Sharon McNeil, and Cheryl Claeys, and Joetta Wallace. Newer members include Jami Gattuso, Linda Abramovitz, and Courtney Sullivan.

In 2004, the Task Force conducted a national survey of APHON members and 75% stated they would like a breakout session at the annual conference on international pediatric oncology nursing.

In 2005, two Central American nurses were supported by outside funders to attend the APHON conference. America Galindo from Guatemala City, Guatemala presented her research on palliative care in children with cancer in Guatemala.



L-R 2005: Ana Orozco Sandino, Managua, Nicaragua, Julia Challinor, Netherlands, and America Galindo, Guatemala City, Guatemala

In 2006, the Task Force encouraged nurses working internationally to submit an abstract for a concurrent session on international nursing at the annual conference. Several abstracts were received and a presentation was given on “International Pediatric Oncology Nursing Collaboration: Challenges, Strategies and Benefits” and a poster was presented on “Children with Cancer in Countries with Limited Resources: How Can We Help?”

In 2006, the Task Force’s action plan to bring a nurse from a low- or middle-income country to the annual

conference was accepted by the APHON Board of Directors and criteria for applications were quickly assembled. A notice of the opportunity to apply for the scholarship was sent out using all the Task Force members’ connections and all Local Chapter Presidents were also informed. Nurses were nominated and Carla Dias, RN, MSN, BSN from Sao Paulo received the scholarship.

In 2007, we received a large number of applications from Ghana, Philippines, Guatemala, Czech Republic, Uruguay and Tanzania. The word was really getting out. The selected candidate was Mary Haule from Ocean Road Cancer Center in Dar es Salaam, Tanzania.

In 2008, an article on “Multicultural nursing: More than just speaking the language: Practice in the U.S. with families from other cultures” was solicited from the Task Force and published in APHON Counts.

Throughout the years, APHON has continued to offer the scholarship for the annual conference to an international nurse. Nurses have come from Ghana, South Africa, Jordan, Saudi Arabia, and Botswana. The accomplishments of these pediatric oncology nurses have grown over the years and the competition for the scholarship is very high. The Task Force chooses the candidate they believe will be best able to share their experience and knowledge gained with other nurses in their country and region caring for children with cancer.

In 2010, Joetta Wallace was appointed as the first chair of the International Task Force.

In 2011, APHON generously donated multiple copies of the “purple book,” *Nursing Care of the Child and Adolescent with Cancer*, and the about-to-be re-published, *Biotherapy and Chemotherapy Curriculum*. Copies of these books were distributed at the SIOP Africa congress in Cape Town in 2012 as well as other networks of international pediatric oncology nursing collaboration (e.g., The Aslan Project in Ethiopia and St. Jude Children’s Research Hospital global partners.)

In 2014, due to increasing requests from nurses around the globe to access APHON’s resources, APHON enlisted the help of the International Task Force to develop and



L-R 2016: Rich Ramos, Janie Avila and Courtney Sullivan with the first cohort of the APHON Biotherapy/Chemotherapy Spanish course at the Calvo Mackenna Hospital in Santiago, Chile, April 2016.

pilot the APHON Chemotherapy and Biotherapy Pediatric Provider Course in Latin America, following the translation of the textbook into Spanish by the Medicine Patient Services at Boston Children’s Hospital in 2013. Courtney Sullivan from the International Outreach Program at St. Jude Children’s Research Hospital, and member of the Task Force, coordinated the project that was conducted over 1.5 years. In preparation for the pilot, a needs assessment was conducted to verify the need for and interest of Latin American nurses in the course. Next, two Chilean nurse educators, Lorena Segovia Weber and Paola Viveros Lamas, involved in training nurses throughout Latin America, took the course in English in the US and provided recommendations for adaptation. The Task Force then worked over many months, with Kristin Belderson’s unflagging and invaluable help as Chair of the APHON Chemotherapy Committee, to adapt the content and the course was professionally translated through support from St. Jude Children’s Research Hospital .

April 25-27 and May 2-4, 2016, marked the inaugural APHON Latin American Chemotherapy and Biotherapy Pediatric Provider Course pilot at Hospital Luis Calvo Mackenna in Santiago, Chile. Each 3-day cohort included culturally adapted lectures and interactive activities in Spanish. The course was taught by two

outstanding bilingual certified APHON instructors of the English-course: Richard Ramos and Janie Avila.

Thirty-one pediatric oncology and bone marrow transplant nurses and nurse leaders successfully completed the course. All involved felt that the course met a need, was comprehensive, culturally appropriate, and enhanced recognition of nurses within the institution.

“We had hoped the course would go well but were pleasantly surprised at how well it actually went. There is something to be said when nurses from various countries come together to pursue knowledge which will shape practice, and the value when institutions and associations like APHON support and invest in nursing education and practice internationally – it is truly inspiring,” says Sullivan.

The Task Force next plans to pilot the Spanish course in other Latin American countries, with the ultimate goal of developing a sustainable course in the region.

Abramovitz adds, “I am excited to celebrate APHON’s 40th anniversary. Throughout my career I have been a member of APHON and more recently a member of the International Task Force. My experience with the International Task Force has been extremely rewarding. Our group met the challenge of revising the chemotherapy/biotherapy course adapting the curriculum to be

both culturally and clinical relevant for the pediatric oncology nurses working in South and Latin America. As a member of the SIOP Nursing Committee and cochair of the Pediatric Oncology Developing Committee Nursing Working Group, I have relied on numerous materials and documents developed by the APHON members and organization. Nurses in low and middle-income countries (LMIC) feel that the information from APHON serves as a valuable resource and provides a good foundation on which to build their practice. The most frequently used resources I have use in my collaboration with the nurses in Asia and Africa included the “purple book,” numerous articles from the *JOPON*, *Scope and Standards*, *Essentials of Pediatric Hematology/Oncology Nursing: A Core Curriculum*, *The Pediatric Chemotherapy and Biotherapy Curriculum* and the *Pediatric Palliative & End-of-Life Care Resource*.

Thank you APHON for 4 decades of excellent work to improve the lives of children and families facing cancer.”

Challinor says, “As a long-standing member of the APHON International Task Force, I am proud of the achievements we have accomplished to date. This would not have been possible without the hard work of all Task Force members and APHON staff, especially Dave Bergeson, who support our work so diligently. APHON’s name, mission, and educational resources are well known throughout the pediatric oncology international community. We appreciate all the international nurses who have attended the APHON conferences and shared their experience and learning with so many other nurses in countries with limited resources. As a group, the Task Force continues to strive to meet the requests for sharing APHON’s vision and resources across the world.”

# APHON's Legislative Advocacy

Jami Gattuso, MSN RN CPON®



Happy 40<sup>th</sup> Birthday APHON!! It's amazing to me to think about how much change and growth we have seen in our organization over the decades...and it pleases me to think what changes we have to look forward to in the future! One area that has seen a tremendous amount of change is legislative advocacy. APHON currently has a truly solid strategic foundation and framework for legislative advocacy, but this has been a long time coming. A number of people have been pioneers along the way—slogging it out in the trenches alone. Those wonderful people are the workers I want to applaud. They are the ones who have made change in the lives of our patients and families by working through our legislative system. I salute them!

If you do a quick Google search for a definition of advocacy, Merriam-Webster tells us that it is “the act or process of supporting a cause...” And I am certain that if you did a search on a definition of nursing, you would find the word advocacy in it. So, advocacy is intimately a part of what we do as nurses. The number of times a nurse advocates for a group of patients during a shift is probably too many to count. I used to teach home TPN administration to patients and families. I recall crying once because the family was to be discharged when they weren't at all ready to take on that responsibility. I was quite young but my tears DID work—so I was advocating

for that family and it paid off! But, of course, that is not the type of advocacy that we are talking about here!

A few years back I learned that APHON had members who represented us at the Childhood Cancer Alliance, which is an advocacy group for children and adolescents with cancer. Beth Siever and Revonda Mosher have been working with the group for years to provide a unified voice from the perspective of nurses who care for these patients and their families. Beth and Revonda are truly pioneers – working long and hard in the advocacy arena! They have attended more Childhood Cancer Action Days on Capitol Hill than you can shake a stick at! Revonda and Beth aren't actually even sure when they started (and they just were plugging away and never imagined anyone would come around asking about dates!). But Revonda recalls initially ordering legislative newsletters from the ANA, ONS, and NAPNAP and writing a brief summary of nursing issues for the APHON newsletter. She then joined the Alliance and attended the Nurse in Washington Internship (NIWI) sometime between 2003 and 2005. There she met with Congressman Albert Wynn from Maryland District 5. He asked her to be on a health-care reform team representing his office! She got Beth involved when APON (before the H!) was being given an award of appreciation for supporting CureSearch and for advocacy efforts. At that time, CureSearch and Candlelighters ran “Gold Ribbon Days” on the Hill. Beth went

and learned about the “asks” and how to talk to your representative. She was invited to go to the Hill the second day and off she went! Back in those days there were a variety of individual groups taking issues to the legislators – the Alliance was more of a coalition group offering support.

We have come a LONG way!!! Kara Bryant joined the effort and more and more members are being added to our advocacy team each year. Courtney Sullivan and Beth Savage came on board last year after completing the NIWI program, and we have two more members who had that very opportunity in the spring of 2016: Leslee Bertram and Stacey Crane! The current team created a wonderful legislative agenda to guide APHON for many years to come. We have a quarterly “APHON Advocacy Correspondent” e-mail newsletter that gives us information as well as concrete ways that all of us can voice our concerns to legislators. We even had a letter signing campaign for the Childhood Cancer STAR Act at our annual conference in 2015!! We have joined several more coalitions to insure that our patients have a voice in the legislative arena. APHON’s presence in legislative advocacy started out with a few people and it has evolved over time into a thriving operation! It has always been strong, but the time has come to have a formalized plan and to keep our members informed of the important advocacy being done.

I had the opportunity to attend NIWI in 2014 and I was reminded that we have a responsibility as a profession to advocate for ourselves and for our entire patient populations, not just for our direct care patients. I also learned the importance of having a nice cohesive voice rather than a cacophony. Rather than each nurse in the country (3 million of us!) running to the legislators with our own personal agendas, it’s critical that we come together. Whether that be nursing as an entire profession, nurse practitioners as a group, nurse anesthetists as a group, or pediatric hematology/oncology nurses as a group, it absolutely will be more beneficial if the group gets itself together, sets an agenda, and asks for things with one collective voice. Finding common ground and being in synch are absolute keys for successful advocacy.

Now, I’d like to leave you with some words from Beth Siever, and you can hear her passion and see why our advocacy program is growing. It’s contagious!!! *“I remember that first year going to Capitol Hill with Cure Search (and Kate Schafer who was a heme/onc social worker who worked for CureSearch) and I just wanted so badly to meet with a representative and use the phrase ‘with all due respect congressman.’ And I got to the very first time!!!! LOL!!! I was in awe of those who were already full into it and could articulate and advocate for our patients (like Kate). It was so inspiring to hear them fight on behalf of my patients. ...I was so hooked!!!!”*

## APHON and AMC: A Partnership of Over 20 Years

Dave Bergeson, PhD CAE



As APHON celebrates its first 40 years, it is my pleasure to take a look back on the changing role of staff at APHON and specifically to share some thoughts and memories regarding APHON's relationship with association management. Perhaps the best place to start is at APHON's very beginning, when four pediatric oncology nurses met at an Association for the Care of Children's Health (ACCH) meeting in 1973. In a 2004 issue of *APHON Counts*, Mary Nelson wrote a wonderful summary of the earliest years of APHON (then called APON), including the following: *"These women realized how valuable it would be to have a support network for nurses working in what is, and especially was then, a very difficult field. They planned to have a special interest group for pediatric oncology nurses at the ACCH meeting the following year, and had 40 participants! Goals were set for the group, and a decision was made not to become a subgroup of the Oncology Nursing Society (ONS), which was also forming at that time, but to underscore the uniqueness of pediatric oncology nursing by developing a separate organization."*

As is the case with many successful organizations, there came a point where APHON's leaders realized they needed to hire full-time professional management. While there are many ways to manage an association, most of them are variants of three basic models: member-volunteer managed, employed-staff managed, or managed by an association management company. It is common for associations to be managed solely by volunteers early in their history (as APHON was). In these first few years, associations typically have relatively few programs to manage and are still sharpening their vision. As the association grows, the number of programs increases, the needs of the membership grow, and the task of managing the association becomes too much for volunteers

that have other full time jobs or commitments to manage. Staff is then hired either directly as in the employed staff model or indirectly through an association management company.

In 1985, APON contracted with an association management firm based in Virginia. The rationale for doing so was solid: operating within a framework of shared resources, association management companies provide cost-effective solutions to staffing, equipment, facilities, and budget considerations. Overhead costs for professional services are shared across each of the company's clients, increasing association resources and capabilities, and strengthening each organization's return on investment. Studies have shown that for associations with up to \$5 million in annual revenue, the association management model consistently outperforms the employed staff model.

Unfortunately, despite being set up for success, this partnership did not last. Again, from Mary Nelson's 2004 article: *"In November, 1994, the first year of Casey Hooke's term as president, she was informed that there was a 'discrepancy in the books.' The following month, it was revealed that the 'discrepancy' was an embezzlement of \$300,000 from APON by the president of the management firm. The embezzler had stolen from all of the clients his business served and disappeared (he was later found and sent to prison). The management firm closed and sent all of APON's files to Casey and forwarded their phones to her. Casey became a one-woman management firm. While this would be enough to make anyone want to run away, Casey received many letters of support from APON members, stating how much APON meant to them and how they wanted the organization to survive. Encouraged by this, and with the help of generous donors and a dedicated board, Casey moved ahead to rebuild APON. The Casey Hooke Distinguished Service Award was established to honor Casey's courage and determination."*

Casey Hooke spoke about this turbulent time at APHON's 30<sup>th</sup> anniversary:

*“Our board was upbeat, supportive, and determined. We knew we needed to find a new management company sooner than later. We could function in a crisis mode temporarily but we believed that APON was a strong organization and that to survive, we needed professional management. We considered several companies and did site visits. I visited the Association Management Center outside of Chicago, who managed 20 healthcare-related professional organizations. They saw us as a great opportunity with a strong membership and a great future. We were very different than a fledgling organization struggling to get started. They generously offered to manage us for the first year with payment deferred until the following year. They were very invested in our success and to this day I am so grateful that the relationship worked for both APON and AMC.”*

The relationship between APHON and AMC has indeed worked, and in fact surpassed 20 years a couple of years ago. What has been the secret to this success? Mark Engle, DM CAE FASAE, is one of the owners of AMC and is well-known to current and past board members. He received his Doctorate of Management from Case Western University in 2011, where he conducted research and collected data on how boards can use their limited time to make successful and significant decisions. According to Mark, one of the reasons for the success of the APHON - AMC partnership has been the unique culture and focus of the APHON Board of Directors: *“High-performing boards share a specific set of characteristics that are typically not shared by less highly performing boards. These characteristics include a shared, strategic focus, a culture of learning, self-accountability, and an effective recruitment strategy. Over many years the APHON Board has consistently exhibited all of these traits, and consequently has been one of the highest performing boards we have worked with over the years. It has truly been a pleasure and a privilege to partner with APHON, and I’m very excited about their future.”*

So, when we write about the partnership between APHON and AMC, what exactly does that mean? What does AMC actually do? When you look at the relatively

simple contract between APHON and AMC, much of what we do falls under the purview of the following phrase: “AMC shall perform such duties and services as may be mutually agreed upon from time to time by AMC and APHON.” This means that AMC manages the operations of the association so that our talented leaders can lead, rather than worry about operations. We bring to APHON best practices from the profession of association management and creative ideas and personal experiences from 30 other full-service association partners. Our staff team is full of talented, creative people that have specialized knowledge and experience in areas such as continuing education, association marketing, meeting planning, association financial management, project management, and people management. We like to say that AMC helps APHON and our other association partners “Achieve What You Believe.”

I should add that the contract between AMC and APHON also states “AMC has appointed an Account Executive to handle the Client’s account.” It has been said that there is no more important relationship in a nonprofit association than that between the executive director and the board – when that relationship is strong, everyone can work productively, the mission gets fulfilled, and the organization clicks. I’d like to think that for many years now, well preceding my time, the relationship between not only the executive director and the APHON Board of Directors, but the entire staff team and the larger collective APHON leadership has been one of mutual respect, mutual trust, learning from each other, encouraging each other, and perhaps even inspiring each other.

In our staff team meetings, we talk a lot about these APHON relationships and how they motivate us, inspire us, and drive us. On behalf of the entire APHON staff team, thank you for sharing your vision with us and allowing us to be one small part in the amazing larger APHON team that will achieve a world in which pediatric hematology and oncology nurses are setting, advocating for, and achieving the highest standards of care for children, adolescents, and young adults with cancer and blood disorders and their families.

# It's Time to Advance Biobehavioral Research in Pediatric Oncology Nursing

Marilyn Hockenberry, PhD RN PPCNP-BC FAAN; Ida M. (Ki) Moore, PhD RN FAAN



Over the past 40 years, pediatric oncology nursing research has advanced knowledge about psychosocial responses to life-limiting illness, disease and treatment-related symptoms, decision making and informational needs across the illness trajectory, treatment-associated late effects, and end-of-life care. Findings from behavioral studies have illuminated the importance of supporting parents who frequently experience post-traumatic stress disorder and healthy siblings who struggle with the emotional trauma of their brother's or sister's cancer diagnosis. Symptom science research has characterized the pattern, severity, and clusters of treatment-associated symptoms such as fatigue, pain, and sleep disruption across the treatment trajectory. Finally, late effects studies have delineated the pattern of and risk factors for treatment-related sequelae, and described survivors' knowledge of their disease and treatment. How can biobehavioral research move these and emerging areas of science forward?

Biobehavioral research examines the interactions among biological, behavioral, and sociocultural factors and the impact of these interactions on patient outcomes. Biobehavioral approaches can be used to test the effects of behavioral interventions (e.g., cognitive behavioral therapy) on biological outcomes (e.g., the stress-immune response in parents of children with cancer

experiencing post-traumatic stress symptoms) or to intervene in biological processes (e.g., oxidative stress/inflammation) in order to ameliorate adverse treatment-related sequelae (e.g., fatigue or depression in children and adolescents receiving chemotherapy); and are ideal for characterizing predictors of and inter-individual variability in treatment-related symptoms and toxicities.

Critical to understanding symptom experiences during childhood cancer treatment is the need for exploration of “why” individual symptom differences occur; this will allow us to identify who may be most susceptible to treatment toxicities. Identifying phenotypic alterations in specific biochemical pathways and genetic modulators of treatment-related toxicity could lead to individualized, genome-based cancer therapy that avoids adverse clinical outcomes. Personalized therapy for a highly curable disease such as childhood leukemia that is based on integration of molecular and biochemical tools into clinical practice is within our reach. Exploration of genetic variations and their influence on therapeutic toxicities will pave the way for pharmacogenetic-based individualization of treatment in the future. A current R0-1–funded study by the authors evaluates both phenotypic and genotypic characteristics in children experiencing leukemia treatment symptoms. This study is one of the first to increase our understanding of phenotypic and genotypic treatment-related symptom associations and their ultimate impact on childhood leukemia cure.

Emerging areas of science, such as health promotion in the context of illness, uncovering the molecular and/or cellular mechanisms that underlie the development of cancer-therapy induced adverse sequelae, and early aging phenotypes observed in some pediatric cancer survivors will require state-of-the-art biobehavioral methods. Using state-of-the-science neuroimaging techniques, Nelson and colleagues (Nelson 2016) found lower scores on a neuro-psychological measure of executive function were associated with microstructural brain tissue changes in the prefrontal cortex and longer time off therapy. In a case series study, Taylor and colleagues (Taylor 2015)

found increased levels of oxidative stress and apoptosis biomarkers in cerebrospinal fluid samples obtained from children with acute lymphoblastic leukemia who were experiencing severe methotrexate toxicity. Levels of the oxidative stress biomarker ( $F_2$  isoprostanes) were similar to those observed in children with traumatic brain injury.

What strategies can be used to build successful biobehavioral research programs in pediatric oncology nursing? Similar to behavioral research, it is critical to establish theoretical links and the underlying rationale for theoretical links among key concepts in biobehavioral studies. This frequently requires integrating biological and social/behavioral science and methods. One strategy for overcoming this challenge is to build interdisciplinary teams (team science) that bring together complementary expertise. Collection of human samples for biological assays (i.e., blood, CSF) can be invasive and create risk, particularly in pediatric studies. One strategy for minimizing risk for harm is to identify times when samples can be collected as part of the treatment regimen. For example, we collect CSF samples when children and adolescents with ALL are having diagnostic or therapeutic lumbar punctures. Data analysis strategies take into consideration differences in the biological measure (i.e., biomarkers of inflammation) by treatment phase. Finally, there

are important considerations when planning approaches for data analysis such as controlling for false discovery rate in genetic or epigenetic studies. It is essential to have a collaborator with expertise in advanced statistical methods in order to maximize opportunities for data analysis and minimize threats to internal validity.

The mission of the National Institute of Nursing Research (NINR) is to promote and improve the health of individuals, families, and communities. To achieve this mission, NINR supports and conducts clinical and basic research and research training on health and illness, research that spans and integrates the behavioral and biological sciences, and that develops the scientific basis for clinical practice (<https://www.ninr.nih.gov/aboutninr/ninr-mission-and-strategic-plan>).

Building on a strong history of behavioral and symptom science in pediatric oncology nursing, now is the time to advance the biobehavioral research agenda. Looking forward from APON's 40<sup>th</sup> anniversary, pediatric oncology nurse researchers are challenged to advance our science by integrating biological and behavioral measures, testing interventions that impact biological and behavioral responses, and translating basic science pre-clinical research into clinical studies of children and adolescents with cancer and their families.

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## 40 Years of Advances in Psychosocial Research and Care

Katherine Kelly, PhD RN PCNS-BC CPON®



The psychosocial care of children with cancer and their families has been a longstanding commitment of pediatric oncology nurses globally and of mine personally. I began my career as a University of Kansas junior nursing student when a very large study of the psychosocial impact of childhood cancer was winding down. The study, led by Dr. Shirley B. Lansky and funded by the American Cancer Society, was wide-ranging and aimed at understanding the psychosocial impact of childhood cancer on children, family members, and others in the community. They were also testing novel supportive interventions. The study had a powerful effect on me and our clinical practice.

Our unit held psychosocial rounds weekly from 2–3 pm. The timing coincided with shift change to allow nurses to come in early to attend or to cover so that the day shift nurses could attend. Any team member could place a child or family member's name on the agenda. The team reviewed the child's disease status and then

planned together the best way to address a concern. Sometimes the nurse or other staff member simply wanted an update on how a family was doing after a child's death or how a child was doing after completion of therapy. The key was that the entire team in the room was focused on the psychosocial care of children and families. As a young nursing student, I attended every meeting I could; when I joined the staff after graduation I continued to do so. I had learned the importance of expert psychosocial care.

The multidisciplinary research team at Kansas published a very systematic assessment of the psychosocial impact of childhood cancer on the child and family with publications addressing the impact on school (Klopovich et al., 1981; Cairnes et al., 1982), marriages (Lansky et al., 1978), siblings (Cairns, et al., 1979), and medical (Lansky et al., 1983) and non-medical (Lansky et al., 1979) costs. One of the strengths of this early research was its pioneering interprofessional collaboration. Sometimes studies were led by physicians (e.g., Lansky), and sometimes by nurses (e.g., Klopovich), as well as by members of other disciplines. At around the same time, other investigators – primarily psychologists specializing in childhood cancer – were also reporting groundbreaking research in all areas of the psychological impact of childhood cancer on the child and family (Kellerman, 1980; Spinetta & Deasy-Spinetta, 1981). This is also when (in 1980) Gerald Koocher, published *The Damocles Syndrome*, coining a phrase we still use to define how survivors view their late effects. Interestingly, the majority of studies published in the *Journal of Pediatric Psychology* during this timeframe included very few nursing co-authors or nursing research citations in the study bibliographies. Fortunately, we are now seeing greater focus on interdisciplinary research, which will be critical to make the gains needed to continue to improve child and family cancer experiences.

Nevertheless, pioneering pediatric oncology nurse researchers at this time were breaking new ground in studying psychosocial aspects of childhood cancer. Dr. Ida Martinson focused on home care of the dying child

(Martinson et al., 1978), while others focused their research on hope (Hinds, 1988), resilience (Haase, 1987), and CNS late effects (Moore, 1995). This is only a sampling – a comprehensive listing of nursing researchers working in the psychosocial arena is beyond the scope of this blog. In addition to the nurse researchers leading these programs of research, countless nurses contributed to psychosocial research studies by facilitating patient/family participation, aiding in securing consent, and implementing the studies at the bedside and in the clinic.

As we move forward, a critical challenge is that much of the evidence for what helps patients and families has not been effectively translated into clinical practice. Today, after four decades of psychosocial research paralleling APHON's 40 years, among the interventions not consistently implemented across settings are

- hospital based schooling and/or school re-entry programs
- adequate psychosocial personnel to provide needed evidence-based care
- training for nurses and other team members to provide basic supportive communication to children and families facing the crisis of diagnosis or the anguish of a child's death.

What is now very exciting is a shift in focus to the translation of the research described above into practice recommendations for every child diagnosed with cancer and their family (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). The *Psychosocial Standards of Care Project* has comprehensively defined practice recommendations for the needed psychosocial care of all children and their families. The leaders of this project, Lori Wiener, Mary Jo Kupst, Andrea Patenaude, Anne Kazak, and Bob Noll, were convened by Peter and Vicki Brown, whose son Mattie (pictured) was treated for osteosarcoma at various childhood cancer treatment centers. The Browns noted that while their medical care at these centers met their expectations, the psychosocial care did not. After Mattie's death, the Browns formed the Mattie Miracle Cancer Foundation to assure that every child with cancer and their families receive optimal evidence-based psychosocial care. The standards were developed by teams

of experts who systematically reviewed the evidence and then extracted the basic recommendations for psychosocial care that could be delivered in any size setting. I am happy to say that APHON was the first professional organization to endorse the standards.

The project is now focused on advocacy – to set policy standards that assure all children and families receive needed psychosocial care. To accomplish this, each and every member of the childhood cancer care team must be ready to do their part. Some of this care must be provided by licensed psychosocial experts such as psychologists, social workers, and child life therapists. But much of the basic care can and should be coordinated and/or provided by nurses. As nurses, we spend the most time with patients and families. Nurses can creatively incorporate psychosocial care into their daily routines in the hospital or clinic. If nurses banded together with their psychosocial team members to design care that assures that every child receives the minimum psychosocial standard of care, just think how this might affect the lives of our patients and their families.

Today, as a nurse scientist, I continue to focus on psychosocial care in my research; in my efforts to advance evidence-based care of children and families; and in my mentoring of nurses, nursing students, and other professionals; and in efforts to translate high quality evidence-based care into practice. I invite you to visit the Mattie Miracle Cancer Foundation website ([www.mattiemiracle.com/standards](http://www.mattiemiracle.com/standards)) to read the psychosocial standards of care yourself and decide how you can ensure that every child with cancer and their family will receive the best care possible – care that is both technically and psychosocially excellent.

*This blogger would like to acknowledge and thank Peter and Vicki Brown for their generous permission to include a picture of Mattie for this blog and their helpful suggestions to assure my descriptions of the Mattie Miracle Cancer Foundation and the Psychosocial Standards of Care Project are properly represented.*

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# Evidence-Based Practice in Pediatric Hematology-Oncology Nursing

Marilyn Hockenberry, PhD RN PPCNP-BC FAAN; Cheryl Rodgers, PhD RN CPNP CPON®



Most nurses are aware of the inconsistencies that occur in clinical practice. Patients sometimes tell us, “That’s not how my nurse did it yesterday” or parents display frustration when they receive mixed messages about the care for their child. We often ask our colleagues about the best way to perform a task or post questions on the open forum in APHON’s Member Connection to inquire about practices at different institutions. We can all appreciate the need to identify the best way to provide care for our patients and families.

Evidence-based practice (EBP) is a method to identify best practices through evidence. Florence Nightingale first described using evidence to guide practice more than 200 years ago. In Nightingale’s *Notes on Nursing*, she discusses how nursing is responsible for understanding how to improve the health of patients. In the chapter on *What It (Nursing) is and What It is Not*, she presents the argument that the nurse plays a major role in assisting the patient during the reparative process. Florence describes key elements necessary for this reparative process to

occur: understanding the importance of ventilation and warming, minimizing noise, promoting adequate nutrition, maintaining cleanliness, and careful observation of the sick. These are all rich in evidence. These key elements remain essential evidence-based components of today’s nursing knowledge, which every nurse should have.

Today most nursing programs teach EBP, and information on EBP is found in textbooks, journals, professional meetings, and even on YouTube. EBP uses a synthesis of evidence from research, theories, clinical expertise, and patient preferences and values to identify best practices and aid in clinical decision-making (Melnyk & Fineout-Overholt, 2015). EBP is commonly implemented through clinical guidelines. Clinical guidelines are systematically developed documents for specific clinical conditions that provide recommendations for practice (AGREE Consortium, 2009). The Agency for Healthcare Research and Quality (AHRQ) manages a national guideline clearinghouse ([www.ahrq.gov](http://www.ahrq.gov)) that is particularly useful. The clearinghouse is a publicly available website that contains many evidence-based clinical practice guidelines. During a busy and hectic workday, clinical guidelines are a quick way to identify standards for practice and they often make clinical decision-making easier.

Unfortunately, clinical guidelines do not exist for many clinical topics in pediatric hematology/oncology nursing. When this deficiency is noted, a systematic review should be performed to evaluate the evidence. Systematic reviews are composed of specific steps that include the development of a focused clinical question, methodically searching for the most relevant evidence, summarizing, synthesizing and appraising the evidence, and developing recommendations for practice (Melnyk & Fineout-Overholt, 2015). This work can be done as a team effort within your institution or professional organization. APHON and the Children’s Oncology Group (COG) Nursing Discipline have been leading many efforts to

develop systematic reviews and highlight guidelines that may be applicable to our clinical work.

After identifying evidence for best practices, nurses need to move the findings into practice. Promoting practice change requires engagement from all levels of staff and administration. Successful implementation of practice change includes preparation—including assessment and elimination of barriers—and an evaluation of outcomes (Melnyk & Fineout-Overholt, 2015). Examples of successful practice change implementation within pediatric hematology/oncology include a formal educational intervention to decrease catheter-related bloodstream infections (Horvath et al., 2009) and a formal reintroduction of chemotherapy-induced nausea and vomiting guidelines to improve adherence and decrease errors with anti-emetic orders (Wood, Hall, Hockenberry, & Borinstein, 2015). Celebrating success of staff contributions and goal attainment is also a critical step during the process of implementing practice change (Melnyk & Fineout-Overholt, 2015).

APHON has been committed to disseminating EBP information for years. Dr. Casey Hooke shared evidence-based management strategies for anthracycline extravasation in 2005 in the *Journal of Pediatric Oncology Nursing (JOPON)*. Since that time, there have been several EBP review articles and systematic reviews in *JOPON* and the May/June 2013 issue included systematic reviews on

several pediatric hematology and oncology nursing topics. Recognizing the importance of EBP, APHON created the Evidence-Based Practice and Research Committee in 2011. The committee has reviewed several established clinical guidelines on pediatric hematology and oncology topics, which are listed on the APHON website. To encourage the development of new EBP information, APHON now offers grants to support EBP projects that address clinical practice issues within hematology/oncology nursing.

Everyone has a role in EBP. All nurses should be empowered to identify clinical problems and question best practices. Nurses new to EBP can serve on committees and teams to identify concerns, assist with systematic reviews, and implement practice recommendations. Nurses with EBP experience can lead teams through a systematic review, implementation and evaluation of projects, and dissemination of findings. Expert nurses should provide mentorship to others and advocate for implementation of best practices within the institution.

Pediatric hematology/oncology nurses should never settle for the belief, “This is the way we’ve always done it.” Be empowered to question practice and become involved with EBP. Everyone’s engagement of the process will significantly advance our profession. Expect nothing less than excellence within our profession!

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# How Symptom Management Has Changed

Christina Baggott, PhD RN PPCNP-BC CPON®



“You’ve come a long way, baby!” Those words ring true when I think of the changes in symptom management in APHON over the past 40 years. Unfortunately, the folks of my era know this slogan is associated with cigarettes, a product that I detest. Nevertheless, the words are apropos for my blog post.

What has led to these advancements? I marvel at how communication changes have altered every aspect of our nursing care and symptom management is no exception.

I was not one of APON’s founding members, but APHON and I go back a long way, to 1987. I was flabbergasted when the FAX machine was introduced to our unit (please note: now facsimiles are the object of ridicule in a recent automobile advert). This advancement meant we could more easily communicate with our pharmacists and obtain needed medications for patients in a timelier fashion.

Once clunky cell phones were introduced, we could readily communicate with our colleagues in other cities without the dreaded long-distance charges. This innovation surely promoted the advancement of symptom science, with the ease of spontaneous exchange of ideas. Likewise, e-mail enhanced our abilities to communicate in real time. As an editor of later editions of the “purple book,” I can’t imagine editing the initial editions completely by snail mail.

Of course, this posting would not be complete without mention of the introduction of the Internet. I vividly recall attending an APHON Conference when an announcement was made of how a novel technology, the World Wide Web, would change our nursing practice. Undoubtedly that prophecy was true. Nurses, our colleagues in other disciplines, and most importantly our patients and families, can retrieve timely information and support

24/7 to manage the expected or unexpected toxicities of cancer and its therapy. Even novice techies can now create outstanding patient education materials. Web-based data collection has facilitated data accuracy and analysis to make our symptom management research more efficient and feasible. We can enroll patients in symptom management trials at remote locations without ever meeting them face to face, and, at times, without a single paper document.

Another example of an Internet-related breakthrough in symptom management is APHON's Member Connection. With a quick browse through the topics, you will find countless creative ideas posted by our members. Patients worldwide can benefit through our collective wisdom. The brisk exchange of ideas via Member Connection and other avenues is not without consequence. We all strive to promote evidence-based interventions. However, to date very few of our symptom management interventions have been based on rigorous, large randomized trials. We often settle for making symptom management decisions on the best available evidence. The early implementation of novel interventions can hamper future enrollment on larger randomized trials. One such example is the adoption of chlorhexidine (CHG) bathing. The Member Connection was full of posts with details of the early trials of this intervention. Now that many institutions have endorsed the practice of CHG bathing, it is

difficult to promote enrollment on the existing CHG bathing trial within the Children's Oncology Group.

Finally, with mobile phones and other portable devices, we have the capability of collecting vital data that accurately depicts our patients' symptom trajectories. Currently we know so little about symptom patterns and their underlying etiologies. We have historic data regarding patient reported outcomes (PROs) in our paper-based charts that will surely go unmined. When considering patients' subjective data in electronic medical records (EMR), we must realize that the data points are typically captured sporadically by nurses and other clinicians. To fully understand the patient experience, we can engage patients and their families to systematically track symptoms for their own benefit and to advance symptom science when they have the opportunity to participate in symptom management clinical trials.

Yes, "we've come a long way, baby", but we'll certainly go further. I can only imagine what symptom science will be like in 10 years, or better yet when APHON celebrates an additional 40 years (I may be retired by then). I am proud to be a long-standing APHON member and I get excited by the opportunities for my colleagues—both seasoned and those new to the field. Advancing symptom science promises to be of tremendous benefit to all the patients we care for.

## 40 Years of Advances in Hematology Care

Karyn Brundige, MSN CPNP



Many of us are aware that the outcomes for children with cancer have improved significantly in the past 40 years, not just in overall survival but in decreased toxicity due to the evolution of targeted and tailored therapies. But what about children with hematology disorders, whether acute or chronic, “benign,” or even life-threatening conditions? I’m amazed at the treatment options available for my hematology patients today that didn’t exist 25 years ago when I started as a new graduate nurse. Take a quick journey with me to celebrate some of the advances!

Did you know that in the 1970s, the average lifespan for children with sickle cell disease was only 14 years? The goal of the first sickle cell trial was simple: prevent children from dying of infection. The Prophylactic Penicillin Study (PROPS) conducted in the mid-1980s randomized assignment between penicillin twice daily and a placebo, vitamin C. The study closed early due to an 84% reduction in *S. pneumoniae* infections and no fatalities in the group taking penicillin prophylaxis! I remember this study – and the children I’ve cared for who have died

from sepsis – when I remind families with young children who have sickle cell disease about why adherence to daily penicillin is so crucial. Other amazing milestones of the 1990s included the use of transcranial screening (TCD) to identify patients at risk for stroke who would benefit from prophylactic blood transfusion, approval of hydroxyurea to decrease complications of sickle cell disease by stimulating the body to produce fetal hemoglobin (HgbF), and a multi-center study of bone marrow transplantation that demonstrated children with sickle cell disease could be cured if they received a transplant from an unaffected matched sibling. Very recently we heard the news of gene therapy being used to cure a French teenager with sickle cell disease!

In the early 1970s, deferoxamine (Desferal) began to be used more widely in children with thalassemia to decrease the iron toxicity caused by frequent blood transfusion. Amazing as this treatment was, the daily subcutaneous infusions proved challenging for many patients. I will never forget caring for a teenage girl who

developed debilitating cardiomyopathy secondary to iron overload and eventually died from multi-organ failure. The emergence of a new generation of oral chelation therapy, including deferasirox (Exjade/Jadenu) and deferiprone (Ferriprox), has resulted in both better control of iron overload as well as improved adherence by simplifying the home chelation regimen for patients requiring chronic transfusion. The wider availability of magnetic resonance imaging to measure cardiac and hepatic iron overload provides a more precise and less invasive method of evaluation and has led to earlier initiation of chelation therapy prior to patients' developing iron-related organ damage.

When I consent patients for blood transfusion, I remember my patients with hemophilia. First, there were those who died from HIV, and then there were those who died because of chronic hepatitis infections contracted from contaminated blood products. Advances in transfusion medicine have improved the lives of all children with hematological disorders, from better screening methods to reduce the risk of infection, to computerized provider order entry to increase patient safety.

Hemophilia care has undergone many other substantial improvements in the past 40 years. Families first started "self-administering" clotting factor concentrates at home in the 1970s. In the past two decades the development of recombinant concentrates has greatly improved the safety and availability of therapy. Treatment now focuses on prophylaxis and prevention of long term side effects of the disease, allowing children with hemophilia to lead healthy, active lives. Other recent advances in hemophilia care include better methods to measure and eliminate inhibitor antibodies as well as curative gene therapy trials.

Recombinant technologies have also benefitted my patients with inherited and chronic cytopenias. In the early 1990s I was a primary nurse for an engaging and energetic teenage boy with severe chronic neutropenia who had his leg amputated as a toddler due to a severe infection. Today my patients with congenital neutropenia can receive subcutaneous injections of recombinant human granulocyte colony stimulating factor (G-CSF) to maintain their neutrophil count in a safe range. In a similar

success story, epoetin alfa (Epogen) has become one of the most widely used drugs created through recombinant DNA technology, minimizing the need for blood transfusion to treat anemia in children with chronic kidney disease, AIDS, and myelodysplastic syndrome. And for the 20% of children with Idiopathic thrombocytopenic purpura (ITP) who develop chronic disease, eltrombopag (Promacta) is now available. This oral thrombopoietin receptor agonist was FDA-approved in 2016 for children 1 year and older with chronic ITP, decreasing the need for corticosteroids or splenectomy to manage their disease.

Did you know that aplastic anemia was often fatal prior to the 1990s when immunosuppressive therapy with anti-thymocyte globulin (ATG) and cyclosporine became the standard of care? An astounding array of genetic panels is now available to diagnose patients with inherited bone marrow failure syndromes, as well as screen sibling donors if transplantation is required. We've also learned that bone marrow – not peripheral blood – is the preferred stem cell source for these patients to decrease chronic graft versus host disease and that nonmyeloablative, reduced intensity conditioning regimens improve survival and decrease late treatment-related toxicity. And due to the improved outcome of unrelated donor transplantation, studies are now comparing immunosuppressive therapy to unrelated donor transplant in patients with newly diagnosed aplastic anemia.

Finally, there have also been significant advances in anticoagulation therapy for venous thrombosis. Low molecular weight heparin is now used to both prevent and treat thromboembolic disorders in children and teenagers. The majority of patients no longer need to be hospitalized and can receive therapy entirely as outpatients! New oral anticoagulants, recently approved for adults, are also being tested in children; they can be administered at fixed daily doses and do not require routine laboratory monitoring.

The care of children with hematologic disorders has changed significantly in the past 40 years. I'm excited to watch for the next new therapy or technology that simplifies treatment, improves outcomes, and increases quality of life for our patients and their families.

## 40 Year Perspective on Late Effects and Survivorship

Wendy Landier, PhD RN CPNP CPON®



Forty years ago, I was a senior nursing student, preparing to take my State Boards, and finishing up my clinical rotation in pediatrics. I have a vivid memory from that rotation of caring for a young boy with Wilms tumor – my first pediatric oncology patient. Jack had recently undergone a nephrectomy and would soon be receiving chemotherapy. The mood in Jack’s room was grim. His mother was tearful, his father was pacing back-and-forth across the cramped, dimly lit room, and Jack was whimpering in pain. I felt completely helpless, and was doing my best to hold back my own tears as I checked Jack’s vital signs. On that day, I couldn’t imagine a future for Jack, and it seemed clear to me that his parents were similarly hopeless. And then the most unexpected thing happened: Jack’s physician appeared, along with a throng of medical students and residents, and confidently announced that he had good news! I thought, oh, my - there must have been a mistake with his diagnosis – maybe they discovered that Jack didn’t have cancer after all! But that was not the message delivered in Jack’s room that day. Instead, the message was this: “Jack has cancer, and we are confident that we can treat his cancer. In fact, it is very likely that we can cure his cancer.” This was not at

all what I - or Jack’s parents - were expecting to hear. But when all was said and done, Jack’s physician had laid out a clear treatment plan. And more importantly, he had infused the room with hope. Jack would be enrolled on the National Wilms Tumor Study (Jack was in the second cohort) and would receive three chemotherapy drugs (none of which I had heard of or could remember) over a period of 15 months, along with radiation to his flank that would be given in daily doses starting the next week, for about 4 weeks. I don’t know if there was actual sunshine seeping through the windows by the end of that conversation – or whether it was the shift in mood that made Jack’s room feel visibly brighter. But there was no doubt that a sea change had occurred during those few powerful moments, and that one little boy’s future appeared oh so much brighter than it had before. I was stunned, but also felt proud to be someone who was becoming a part of this incredible machine that was modern healthcare.

I never saw Jack or his parents again after that day on my pediatric rotation. But I did go on to become a pediatric oncology nurse and eventually a nurse practitioner working in late effects. And I have seen many, many patients like Jack over the past 40 years. Based on what I

have learned from those patients, I can surmise that Jack most likely survived his cancer; however, I also know that it is likely that he paid a significant price for his “cure.” We now know that of the three chemotherapy drugs that Jack received (doxorubicin, vincristine, and dactinomycin) – one (doxorubicin) is associated with a significant risk for cardiomyopathy, particularly in children such as Jack who received higher doses at a young age, and especially when given in combination with radiation that may involve the heart (such as the flank radiation that Jack received). We have also learned that radiation given to children who are still growing, especially in the high doses that Jack received (3500 cGy), can have life-long consequences. In Jack’s case, it is likely that he developed significant scoliosis, muscular atrophy, and impaired growth of his trunk; he also may have developed radiation-related skin or colon cancer, or doxorubicin-associated leukemia. Today, as pediatric oncology nurses, we are expected to be knowledgeable about therapy-related late effects, and we have many resources at our fingertips to enhance our understanding, including the survivorship-focused sections of APHON’s *Foundations of*

*Pediatric Hematology/Oncology Nursing and Nursing Care of Children and Adolescents with Cancer and Blood Disorders*. However, many of the late effects of treatment were unknown 40 years ago when Jack was diagnosed. In fact, during that era, most children diagnosed with cancer did not go on to become long-term survivors, and the art and science of survivorship was still in its earliest stages. Today’s treatments have been refined and improved as a direct result of all that has been learned from brave childhood cancer survivors like Jack. And my brightest hope is that tomorrow’s treatments for pediatric cancers will be refined and improved even further, so that someday in the not-too-distant future, we won’t need late effects clinics any more, and someday, the parents of a young child such as Jack will hear a new message: “Your child has cancer, and we have a cure for his cancer. And we are confident that there will be no long-term effects.” When that day comes, I genuinely hope that there is another young nursing student in the room to hear that message. Because on that day, childhood cancer will truly be cured.

## 40 Years of Advances in Palliative Care

Deborah LaFond, DNP PPCNP-BC CHPPN CPON®; Joetta Wallace, MSN RN NP-C CPON® CHPPN



Cancer is still the number one disease-related cause of death in children (Centers for Disease Control and Prevention, 2015). In addition, symptoms related to the disease and its treatment continue to be reported by patients and families as significant causes of suffering. Palliative care (PC) is dedicated to attending to this unacceptable human condition.

Research studies led by interdisciplinary teams, many of which have included APHON members, have been instrumental in establishing the evidence base for state-of-the-art pediatric palliative care. A catalyst for the development of the specialty of pediatric palliative care was the landmark study led by Joanne Wolfe, MD, and her colleagues at the Dana Farber Cancer Institute and Boston Children's Hospital. They demonstrated that children with cancer experienced significant suffering at the end of life and that discussions of choices in care were often lacking (Wolfe et al., 2000). In a follow-up study, Dr. Wolfe and colleagues showed that integration of palliative care improved symptom distress and communication with parents about advance care planning (Wolfe et

al., 2008). The concept of an interdisciplinary team, paramount to palliative care practice, was finely honed in pediatric oncology. Early studies of caregiver burden, parental choices in decision-making, adolescence resilience, sibling support, and self-care for healthcare professionals all started in pediatric oncology. Pediatric oncology has been a pioneer in integrating palliative care for patients with high-risk cancers from the time of diagnosis, extending throughout treatment and hopefully into survivorship, but also at the time of death and into bereavement, if that is the outcome.

APHON was at the forefront of establishing a benchmark for integration of palliative care into the care of our patients. On September 9, 2000, APHON participated with 22 other organizations to promote discussion and establish an agenda for nursing in end-of-life care. APHON collaborated with the Society of Pediatric Nurses (SPN) and the National Association of Neonatal Nurses (NANN) to write the *Precepts of Palliative Care for Children, Adolescents, and Their Families* as an outcome of the Nursing Leadership Academy (Bowden et al., 2003). In the early 2000's, several APHON members participated in the development of the first End-of-Life Nursing Education Consortium – Pediatric Palliative Care (ELNEC-PPC) curriculum. APHON sent multiple members to the first ELNEC-PPC training in California in 2003.

Since then, APHON has been committed to continuing education for members through formal ELNEC-PPC courses. We also have a Member Connections discussion group on palliative care and Town Hall sessions on palliative care at the APHON Annual Conference. Our annual conferences feature increasing numbers of concurrent sessions and pre-conference workshops dedicated to incorporating palliative care into our toolbox of care modalities for children with cancer. In related work, APHON is a member organization of the Patient Quality of Life Coalition (PQLC) and also participates in a SIOF committee, Pediatric Oncology for Developing Countries (PODC). Pediatric oncology nurses in the Children's Oncology

Group and APHON collaborated to publish the “Pediatric Oncology Palliative and End-of-Life Care Resource”, providing evidence-based information to guide supportive care regardless of ability to cure (Ethier, 2010). Pediatric oncology nurses know the importance of integrating prevention and alleviation of treatment side effects alongside aggressive therapeutic approaches.

It’s also fair to say that in a field where palliative care principles are so well integrated from diagnosis onward, we continue to struggle with using the term palliative care. Programs have contrived softer titles in an effort to get away from the notion that palliative care is the same as end-of-life care, but pseudonyms have not been successful in solving the problem. Another ongoing challenge is when to add the specialists in palliative care to the pediatric oncology healthcare team. We still hear oncologists saying that it is “too early for PC because we have another therapy option,” and “I’m not ready to give up yet...neither are the parents or the patient.” It is commonly said that “PC is too early until it is too late,” when the symptoms of end-of life care override meaningful time that the patient and family could spend doing something they would value. The American Academy of Pediatrics, the National Academies of Science, Engineering and Medicine (formerly the Institute of Medicine), and the Center to Advance Palliative Care (CAPC) clearly state that palliative care should be offered at the time of a cancer diagnosis (Feudtner, 2013; IOM, 2015; CAPC, 2017) But PC continues to be perceived as unwanted or

unnecessary early in the child’s treatment, even in light of recent studies which established parents and the patients themselves had little opposition to early palliative care involvement and believed their symptoms of suffering could have been better managed by these professionals (Lafond, 2015).

An emerging issue is the role of PC for childhood cancer survivors. There are late or lasting effects for some cancers and disease-related therapies that constitute complex chronic conditions that young people will live with into adulthood. PC is now being considered the standard of care for symptom management to minimize distress and suffering for individuals with conditions such as these (Meier, 2004).

The key platforms of palliative care are symptom management, helping with patient/family goals of care and interdisciplinary coordination through excellent communication to promote comfort and optimize quality of life throughout the trajectory of the cancer experience. These are fundamental to all pediatric cancer management and should be incorporated into the skill set of all pediatric oncology nurses. The addition of the specialty service of palliative care provides an extra layer of support to the patient, the family, the healthcare team and the community. We are proud that pediatric oncology nurses, and our professional organization – APHON – have helped blaze the trail for the integration of palliative care into clinical practice.

## Evolution of Advanced Practice Roles Over the Past 40 Years

Deborah LaFond, DNP PPCNP-BC CHPPN CPON®

I guess you could say that my claim to fame is being the first pediatric oncology nurse in the United States Air Force. As a relatively new nurse, only a few years out of nursing school, I joined the Air Force to see the world and experience a different kind of nursing. Well, that wish surely came true. In those days, the Air Force could assign you a host of responsibilities that a typical bedside RN did not necessarily have the training to do. However, I worked with a dedicated pediatric oncologist who sent me to UCSF to train under the very capable supervision of Robin Kramer. That was my first introduction to the fascinating and rewarding world of pediatric hematology/oncology nursing. It formed the foundation for a career that has spanned 3 decades. My role in the Air Force provided me with the opportunity for autonomy, creativity, and program development as a staff nurse. Today, we would call this role a clinical coordinator or clinical nurse educator. That role opened my eyes to the possibility of advanced practice.

My husband was transferred to Hawaii with the Air Force in the early 1990's. During that time, I had the opportunity to attend the University of Hawaii for graduate school, where APHON's own Carol Kotsubo became my clinical preceptor in the NP program. She is the one who told me about APHON and the benefits of a specialty nursing organization. I joined right away, but as a relatively new NP, was a bit intimidated by the very experienced APHON members who were doing so many great things, so I began my work in APHON quietly. I got involved in reviewing a document or participating in planning the annual conference, but never wanted to be more than a worker bee. I should have known that the great APHON leaders would not sit still for quiet members! I moved to Children's National in 1992, where a very enthusiastic APHON member, Debbie Freiburg, insisted that APHON needed people like me in leadership positions, not just as quiet members. She encouraged me to get more involved in the organization.

Be careful what you wish for, because I listened to her and delved right in. The first APHON leadership

opportunity was being elected a member-at-large on the APHON Board of Directors. This was a wonderful experience, where I was able to witness first-hand the workings of the organization and see that the mission resonated with my own values for providing the highest quality of care for children with cancer and blood disorders, and their families. I was able to be a liaison to the Oncology Nursing Certification Corporation during the initial CPON certification days. This provided me with the opportunity to better understand and champion the benefits of specialty nursing certification. But, the most important opportunity that APHON provided me was to attend the first End of Life Nursing Education Consortium – Pediatric Palliative Care Training (ELNEC-PPC) in 2003. That set the tone for the passion of my career and ignited a fire for advocating for palliative care for all children with high-risk and relapsed cancers and other serious life-threatening illnesses.

I was able to represent APHON with Susan Dulzack at the Nursing Academy of End-of-Life Care in 2003. Together with the Society for Pediatric Nurses (SPN) and the National Association of Neonatal Nurses (NANN), we developed the collaborative *Precepts of Palliative Care for Children, Adolescents, and their Families (2003)*. This document has become the foundation for pediatric palliative care initiatives throughout the nation, and later the APHON-COG *Pediatric Palliative & End of Life Care Resource*. For me, this experience showed that if we want to provide the highest quality of care for our patients and families, then we need to be involved in clinical care, advocacy, research, and education.

I saw all of these roles illustrated through the visionary leaders of APHON. I was exposed to nurses, just like me, who were not only going to graduate school for Master's level preparation, but were seeking doctoral level education as well. I said at the time, "NO, not me! I am never going back to school!" Never say never! I watched as leaders such as Pamela Hinds, Kathy Ruccione, Casey Hooke, Wendy Landier, and so many others, walked their doctoral journey and bore witness to a generation of

nurse leaders with a passion to generate new knowledge in caring for children with cancer and blood disorders. This was intriguing, but somehow did not quite resonate with me. Then, along came the Doctorate of Nursing Practice degree. Bingo! This was it. The DNP degree fanned the fire and resonated within me.

So in my later career, I went back to school and graduated with my DNP in 2012. What I see as the value in this degree is translational research. I like to think of the great minds of Dr. Hinds, Dr. Ruccione, Dr. Hooke, Dr. Landier, and others, generating new knowledge, and then the DNP taking it to the bedside and really studying how that new knowledge can impact nursing practice and most importantly, improve patient outcomes. So, as I move into this phase of my career, I have had the very unique opportunity to serve as the first chair of APHON's

Evidence-Based Practice and Research Committee. This has been a humbling and rewarding way to impact care across the nation as we review, develop, and disseminate the most current clinical guidelines and research relevant to the care of pediatric hematology/oncology patients.

So, to summarize, find your passion as a staff nurse in pediatric hematology/oncology. Develop your own path to advanced practice that resonates with your goals and look to doctorally prepared nurse leaders within APHON to not only generate new knowledge, but translate it into meaningful ways to impact patient outcomes. As the old camp song says, "it only takes a spark to get the fire going!" APHON gave me that spark and developed me into what I hope has been an impactful nurse leader for children with cancer and blood disorders. Thank you APHON for 40 wonderful years of fanning the flame.

# The Evolution of Decision-Making and Consent/Assent During APHON's 40 Years

Katherine Kelly, PhD RN PCNS-BC CPON®; Kimberly Pyke-Grimm, PhD(c) RN BC-CNS

**Kim:** It was in the early 90's when I first began to work with my mentor Dr. Lesley Degner, PhD RN, in Winnipeg, Manitoba, Canada, to study treatment decision-making (TDM) in pediatric oncology. Dr. Degner had conducted decision-making research for many years in adult oncology. Through her mentorship we conducted a study where we applied her control preferences construct to pediatric oncology. Little did I know decision-making would become my life's work!

I met Kathy Patterson Kelly at a Children's Cancer Group (CCG)\* meeting when I was giving a talk on TDM. (I will never forget how Fran Wiley, another lifetime nurse mentor of mine, carried and calmed my baby outside the room while I gave my talk.) After the talk, Kathy approached me about her interest in collaborating. We forged a team and subsequently, Dr. Janet Stewart, another formidable researcher, joined us. We often referred to ourselves as "the three-headed dog." Those of you who are Harry Potter fans will understand this analogy. The three of us became steadfast friends and colleagues. We were able to obtain small grants to study parental treatment decision-making. We have since expanded our population of interest to include children, adolescents, and young adults.

The inclusion of children and adolescents in TDM is now promoted through professional organizations, government agencies, and ethical as well as legal perspectives. The United Nations Convention on the Rights of the Child is one example (<http://www.ohchr.org/en/professionalinterest/pages/crc.aspx>). Different countries, cultures or ethnic groups may have varying viewpoints, approaches, and understanding about this topic. Research focused on TDM in children and adolescents is still in its infancy. Investigators have focused on pediatric assent, staging the consent process, and use of short forms summarizing the clinical trial and other interventions to facilitate parents' understanding. Dr. Eric Kodish, a pediatric hematologist-oncologist and ethicist, has led NIH-funded pioneering multisite studies of informed

consent in childhood cancer. His research has been seminal in influencing the consent process in clinical research. Interestingly, the study team reported findings from their study of communication of randomization in clinical trials for children with ALL that the presence of a nurse during the consent conference was strongly associated with greater parental understanding of randomization (Kodish et al., 2004).

Over the past several decades, valuable research in treatment decision-making has been conducted by nurse scientists including Dr. Pamela Hinds, Dr. Faith Gibson, Dr. Janet Deatruck, Dr. Roberta Woodgate, and Dr. Imelda Coyne – to name a few. Each has moved the science forward to better understand the process and outcomes of cancer treatment decision-making in pediatric oncology. Various studies have focused on decision-making at the end of life, clinical trials and minor decisions related to cancer treatment.

We three nurses (Kathy, Janet, and myself) have witnessed tremendous change over the lifetime of our clinical practice. Years ago, children were not always told they had cancer, but today clinicians strive to include them in sharing information about their disease and treatment, as well as discussions and decision-making about their cancer treatment. We have come a long way.

More and more we realize the importance of communication and information exchange as it relates to treatment decision-making, as opposed to a one-way delivery of information from provider to patient or family. The role of family and their relationship with the health-care provider throughout the child's continuum of care must also be considered because they are important elements in understanding the decision-making process. We have made great strides in understanding treatment decision-making in pediatric oncology. Findings from the past and future studies will help to identify important areas on which to focus interventions for many years to come.

**Kathy:** Yes, I was very much intrigued by Kim Pyke-Grimm's talk at a CCG meeting that I was attending representing the former Pediatric Oncology Group (POG)\*. I had heard her present her research findings at an APH-ON meeting earlier that year. Her findings rang true to my clinical experiences and I was very interested in learning more from her. Kim and I had lunch with her infant son next to us in his buggy. Reflecting back on this meeting more than 17 years ago, I am so grateful for my willingness to walk up to Kim, discuss her work, and suggest that we collaborate on future research! You never know how professional friends and collaborators can shape your career.

When the new Children's Oncology Group and the Nursing Research Scholars program were formed, Kim and I wanted to join that group! That's when we approached Janet Stewart, with her newly minted PhD from the University of North Carolina AND a longstanding POG-friend of mine, to join our team. Janet's work on child uncertainty was a good fit and we then embarked on several studies together. For years the three of us had regular conference calls to complete our work and forge our – still to this day – strong friendships. We've seen each other through one secondary data analysis, two funded pilot studies, one state of the science summit, five-plus manuscripts, numerous abstracts and presentations, and a couple of unsuccessful attempts to fund an approved COG Nursing Research Concept. We've also seen each other through marriages and divorces, the birth, graduation, college acceptances of our children, (not yet ready for marriage and grandchildren – but soon) and all of their wonderful accomplishments, career moves, graduate school, and more recently greater success in obtaining the necessary grant funding to advance our programs of research. Kim and I

continue to collaborate as we have moved our research focus to child, adolescent, and young adult treatment decision-making.

When I started in pediatric oncology in 1980, assent was not a formalized process. An ethicist from my hospital, Bill Bartholomew, was working at the national level to formalize assent for every child. His early writing and advocacy, along with that of many others, created the process we know today. Kim mentioned the work of Eric Kodish and his co-investigators. Their work also changed the consent process as we know it today. When I began my career, consent was combined with informing parents – for the first time – about their child's diagnosis of cancer. Dr. Kodish's work led to the recommendation of dividing this process into two family meetings, first to talk about the diagnosis and then coming back a second time to discuss participation in available clinical trials. Parents uniformly told us that after hearing the word cancer, nothing else sinks in. Allowing some time for parents to absorb the shock of the diagnosis permits a better chance to seek truly informed consent from them about their child's participation in a clinical trial. Early on, children were rarely involved in these meetings, but this is changing as well.

I am thrilled to be part of a larger community of researchers who are now seeking child and adolescent voices to identify their preferences for being involved in their treatment decision-making. Based on our early findings, we are learning from the children directly how they view this process and also learning that they have very individualized preferences. We are pursuing funding to learn more about this. I think the next horizon will be combining, parent, child, and clinician voices to determine how the family engages in decision-making together when a child is diagnosed with cancer.

*\*Two of the legacy pediatric cancer clinical trials groups that merged to form the Children's Oncology Group*

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## 40 Years of Building a Legacy

Kathy Ruccione, PhD MPH RN CPON® FAAN

I am deeply grateful to the APHON nurses who shared their recollections through these 40<sup>th</sup> anniversary blog posts. Their blogs have touched on many of the transformational accomplishments in pediatric hematology-oncology nursing over the past 4 decades. Our stories are an important part of the legacy – the professional hand-off – we leave for our colleagues in the years ahead. The common threads running through the blog posts are our shared commitment to providing excellent clinical care, pursuing nursing research and translating evidence into practice, being lifelong learners, and taking care of ourselves and each other so we can be and do our best. Naturally, we all hope that someday cancer and serious blood diseases will not be a part of anyone's childhood. Meanwhile, what legacy do you hope to leave for the future?

Here are some of my thoughts.

One rainy spring day, an eagerly anticipated ritual begins in a preschool classroom as a little boy stretches his arms straight out with his hands palms up to accept the globe his teacher places there, his small serious face registering the concentration needed for the task. Balancing the globe and carefully placing one foot in front of the other, he slowly walks heel-to-toe in an elongated circle around the candle, representing the sun, in a saucer on the linoleum floor. When he completes one lap, the teacher asks the children how much time it took for the earth to go around the sun. They shout, "1 year!" He makes the circuit 3 more times, pausing as he completes each full cycle so the children can count out how many times the earth has rotated around the sun since he was born. When he completes the fourth turn, the children begin to sing "Happy Birthday," already anticipating their celebration with the cupcakes and juice waiting on the table nearby. As I watch, I think about the boy's future – and I remember another song, the one that starts, "he's got the whole world in his hands, he's got the whole wide world in his hands..." I wonder what lies ahead for this birthday boy – when he has completed his allotted earthly trips around the sun, how many lives will he have

touched with those hands and how will the world be better because of his presence in it? And then I look at my own worn hands and think about how many times I've traveled around the same sun.

Nothing bespeaks nurses and nursing to me more than hands. Images of nurses' hands are burned into my mental hard drive, as retrievable as a teenage girl's cell phone photos. Maybe that's because I stared endlessly at so many hands while my own naive hands were gradually metamorphosing into experienced nurse's hands. Looking at neatly trimmed fingernails, skin of every hue, plain watches with sweep second hands, blue-green traceries of veins, modest engagement rings and wedding bands, hands of women and hands of men, I was always fascinated to think that so much dexterity, skill, and tactile experience could be contained in such ordinary-looking hands. There was the charge nurse on the peds unit whose hand held a particular kind of fine point felt-tip pen that she used to grid a sheet of notebook paper at daybreak as she took change-of-shift report, orchestrating a crushing to-do list of IV fluids, meds, and procedures – calmly making the day look manageable because it could be mapped out so capably. There was the L & D nurse whose hands were poetry in motion as she selected exactly the right supplies, deftly opened sterile packaging, positioned lamps, and arranged everything that would be needed in perfect rhythm with a newborn's imminent delivery. And there was the pre-anesthesia nurse with the almost psychic venipuncture skills, gliding an IV start effortlessly, painlessly, beautifully with her amazing hands. Of course, there was also the scary Cruella De Vil night nurse of my student days, whose long, curving red-enameled fingernails were her trademark. One evening, as I watched, she cut a piece of tape to stabilize an NG tube (apparently not having mastered the nursing expert competency of tearing tape), simultaneously severing one of her prized fingernails. In stunned silence, we both watched it arc through the air and land precisely in the emesis basin with a little "plunk."

Then there were the capable, no-nonsense hands of the African-American nurse I worked with as a new grad. I first noticed those hands as she sculpted the avocado she brought from home for her supper every day. I was mesmerized as she sliced it open, removing the pit in one smooth motion, and then – using the rough outer skin as a bowl – she ate the fruit a spoonful at a time. Truthfully, I was just as spellbound by her dinnertime conversation with another nurse. They talked about people I assumed were neighbors and friends who led very complicated and dramatic lives. Someone was having a long-term affair with someone else’s husband, someone was diagnosed with a fatal illness, and someone else had amnesia. Several avocados later, I came to understand that the intriguing conversation was really about a TV soap opera. Anyway, it was her hands that taught me so much that summer. They were hard-working and wasted no motion, yet they found a few moments even on the busiest days to do the little things that made her patients more comfortable: smoothing lotion on dry skin, replacing a damp pillow case with one that was clean and fresh, combing a grandmother’s hair before visiting hours, feeding the man recovering from a stroke while recounting a story to distract him so there wasn’t any loss of dignity, finding a coloring book and crayons for a scared little girl.

I rotate my hands now and examine the life-line traversing my palms, thinking that what novice nurses can’t know is how quickly their trips around the sun will add up. And that as time goes by, it will feel like those trips are faster and faster. Only yesterday it seems, I stared at my reflection in the full-length mirror, transfixed by the student nurse uniform being pinned for hemming in a dark and cramped garment district store, wondering how my 17-year old self could possibly pass for a health-care professional. Only yesterday, on a hot August afternoon I woozily awoke to the piercing fumes of ammonia smelling salts after watching the lab tech draw my blood for my nursing school admission H & P - clearly not the best way to demonstrate I had the “right stuff” to be a nurse. Only yesterday, I practiced slapping my first pair of shiny silver bandage scissors into an imaginary physician’s hands and placing them in the special loop of

my uniform pocket before I walked up the steps to my first day on the floor. Only yesterday, I spent every moment I could spare on a busy unit rocking the sweet baby boy with Down syndrome and a weak heart who never had a visitor. Only yesterday, I rested my hand on a young man’s shoulder as he got his chemo “push” – tables turned, this same young man was the physician who had saved my life after a crash C-section. Only yesterday, I spoke with the girl who could not hear her nurses and would not get out of bed, my hands explaining that if she got up and walked, her post-op recovery would go better and she could go home sooner. Only yesterday, I turned the pages of “*The First Dog*,” as I read this favorite book for the rapt little boy who had just had his seventh surgery. Only yesterday, I showed another nurse how to do something I’ve done a thousand, a million, times. Only yesterday, I held hands with the daughter whose mom was my good friend – sharing her sorrow as she scattered her mother’s ashes into the Pacific. I look around me and nurse friends are joining AARP and retiring to Palm Springs. All in the blink of an eye.

As nurses, we are creating our legacy with our hands and, in fact, by every action every day. I think of nurses’ hands and their heritage of technical artistry, composure under fire, authentic clinical expertise, efficiency, empathy, compassion, and healing. These are the gifts of our shared nursing legacy that I want to pass along, too. Still, I imagine that the majority of patients would not know or could not name all the nurses whose hands have touched them. Most people would not be able to name any notable nurses, other than Florence Nightingale and Clara Barton. And almost none could list the major nursing contributions to health and health care in the past 50 years, including developing or substantially changing critical care, palliative care, and birthing, as well as using nursing research to define evidence-based practice and demonstrate the difference that nurse staffing and education make to patient outcomes. Nurses tend not to claim credit for much. Though I can dream that my legacy as a nurse will be to improve, illuminate, inspire, or influence nursing practice – mostly I hope that if I am remembered it will be because I could find silver linings, laugh often, lighten someone’s burden, share what

I've learned, and treat each individual with care and respect. So, when I look at my own hands I think of all the lives that have touched mine and that I have touched: patients, colleagues, friends, family – those who made many orbits around the sun and those who departed before even a single turn was done. In the end, I marvel at the thought that our most amazing legacy might be microscopic; if indeed it's true that we exchange molecules every time we touch each other, it would mean

that we always carry with us a bit of everyone we've ever touched, and they have received a vital part of ourselves. And that would be a most fitting legacy because, as nurses, we do have the whole world in our hands.

Happy birthday, APHON – wishing you many more productive and satisfying trips around the sun!

*Note: adapted from an essay written for Nurses Week at Children's Hospital Los Angeles, 2006.*





