



The APHON Advocacy Correspondent

Welcome to the Advocacy Correspondent, a quarterly offering from the Association of Pediatric Hematology/Oncology Nurses. The goal of this newsletter is to inform members about legislative and regulatory issues impacting the profession of pediatric hematology/oncology nursing and the patients we serve.

**Send your health policy and advocacy news to Jordan at jwildermuth@aphon.org.*

APHON Legislative Action Center Launched

APHON recently launched its [Legislative Action Center](#) to offer a quick and easy way for members to send communications to policymakers as well as to track legislation relative to APHON's policy priorities.

APHON Inaugural Lobby Day

By: Beth Siever & Kathy Patterson Kelly

This year Congress and policymakers are considering several important initiatives that could significantly support the development of new innovations in the care and treatment of pediatric cancer patients and their families. On September 20th, at the height of Childhood Cancer Awareness month, APHON held its first Lobby Day in Washington DC. APHON members Kathy Patterson Kelly (DC), Sarah Kaczor (Virginia), Lori Wecht (Florida), and Beth Siever (Maryland) along with APHON staff member Jordan Wildermuth took to Capitol Hill to let our congressional representatives know that the pediatric hematology/oncology nurse's perspective is essential in the development of current legislative initiatives that affect our patients and families. We met with five Senators and six Representatives to advocate for Congressional support of two bills supported by APHON: the Palliative Care and Hospice Education and Training Act (H.R. 3119 / S. 2748) as well as the Childhood Cancer Survivorship, Treatment, Access, and Research Act (H.R. 3381/S. 1883). APHON's inaugural Lobby Day was a successful first step in ensuring pediatric hematology/oncology nurses are part of the conversation when key initiatives affecting our patients and their families are making their way through Congress.

To prepare for Lobby Day, the attendees took part in a webinar training one week prior as well as a briefing the morning of Lobby Day. In order to coordinate meetings and to ensure that first time advocates were matched up with veteran advocates, the group was split into two teams. In this format, team members were able to complement each other's knowledge and expertise as it related to APHON's message. As a first time legislative advocate, Kathy Patterson Kelly enjoyed the discussions with the legislators' staff members. It was impressive that many of the staff members were either already familiar with the two bills or very interested in hearing more about the bills. A couple staff members asked us to send them specific information regarding the legislation. One member of our delegation, Lori Wecht was very effective during the visits as she could speak from being both a pediatric hematology/oncology nurse and the parent of a pediatric brain tumor long term survivor! The staffers paid particular attention to her story and discussion of the bills.

One of the group's favorite offices was Congressman Charlie Dent from Pennsylvania who had a beautiful child painting of a gold ribbon! It turns that Congressman Dent's wife works to raise funds for childhood cancer in her state. Kathy left her gold ribbon lapel pin with the staffer receptionist!

We had a great debriefing at a historic Irish pub that is located in the shadow of the capitol dome. There we discussed our visits and planned the follow up we needed to do the following day. Each of us vowed

to return next year.

Post-Election Rundown

By: Jordan Wildermuth, Health Policy & Advocacy Manager

As the dust settles and both parties begin to lick their wounds from the 2016 election cycle we look ahead to the Lame Duck session and what a Trump Administration might look like. Things that were on the table for the Lame Duck have been moved off because of the fact that Republicans are now in the majority of both the House and the Senate as well as the presidency. One of the most imminent issues was the appointment of Merrick Garland to fill the Supreme Court vacancy due to the passing of Justice Antonin Scalia. The Senate will hold out on confirming a new Justice until President-elect Trump takes office because a Trump appointee will be more conservative and will be able to move quicker through the Senate confirmation process in the next session. Additionally, the negotiations of the Trans Pacific Partnership are now off the table as Trump has indicated that a goal for his administration is to review all trade agreements. So what will be discussed during the Lame Duck? A spending bill is top of mind as well as the 21st Century Cures Act which Sen. Mitch McConnell (R-KY) has indicated is one of his priorities and will likely be a parting gift for the bill's sponsor, retiring Congressman Fred Upton (R-MI). The 21st Century Cures Act establishes a NIH and Cures Innovation Fund to 1.) Appropriate funds for biomedical research, including high-risk, high-reward research and research conducted by early stage investigators and 2.) Develop and implement a strategic plan for biomedical research.

A Continuing Budget Resolution (CR) was passed in September 2016 that would fund government agencies at the Fiscal Year (FY) 2016 level through December. There are two options for Congress to pursue during the Lame Duck. The first would be a short-term CR that would fund government agencies into the new Congress which would allow the new administration to be part of the budget negotiations for FY 2017. The second option is a longer CR that would provide funding through March 2017 at which time the agreement to suspend the debt ceiling limit expires. Either way there will be some sort of CR with the goal to return to the normal appropriations process.

The 21st Century Cures Act is a bipartisan measure that is now being framed as a way to carry out the Cancer Moonshot Initiative. There is a lot of support for this legislation and its fate will come down to whether or not there will be enough time to iron out the differences between the House and the Senate and deliver it to the President's desk on time.

One other product of the election that will occur in the next month is the appointment of new committee chairs to replace those Members of Congress that are retiring. The two most sought after seats and important to APHON are the House Energy & Commerce (E & C) Committee and the House Appropriations Committee. The E & C Committee is important because it has jurisdiction over food and drug safety as well as public health research and oversees the Food and Drug Administration and the Department of Health and Human Services. The House Appropriations Committee is important because it has jurisdiction over the annual appropriations measures which includes the provision of funding for departments and agencies. Three individuals, Reps. Greg Walden (R-OR), John Shimkus (R-IL), and Joe Barton (R-TX) are all in the running to replace Rep. Fred Upton (R-MI) as chair of E & C. On the Appropriations Committee, retiring Chair Hal Rogers (R-KY) is likely to be replaced by Rep. Rodney Frelinghuysen (R-NJ) who is the most senior appropriator on the committee. There are also some leadership positions being jockeyed for but it looks as though Sen. Chuck Schumer (D-NY) will become the Senate Minority Leader and Sen. McConnell will remain as Majority Leader. On the House side there has been speculation that Speaker Paul Ryan will be replaced due to his lack of support for Trump on the campaign trail, but as of late it seems as though President-elect Trump and Speaker Ryan are burying the hatchet and looking to move forward on a united front. We will also be looking to who Trump appoints as the next Secretary of the Department of Health and Human Services and if the repeal and replace of the Affordable Care Act moves forward, although President-elect Trump has signaled his willingness to keep some of the most important aspects for children/AYAs including the ability of young adults to be covered under their parents' plan and not allowing for the denial of insurance coverage based on the presence of pre-existing conditions.

What does this all mean for APHON? Despite the uncertainty surrounding healthcare issues, there remains bipartisan support for pediatric hematology and oncology issues such as the Childhood Cancer STAR Act and the Cancer Moonshot. The fight will be on the appropriations side as it has been for the last eight years with disagreement over spending levels for government agencies and the lack of funding for new programs. APHON will continue to work with our partners 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.

Legislative Tracking Chart

Find out more about bills that have been introduced during the current Congress that could have an impact on pediatric hematology/oncology nurses or our patients by utilizing APHON's [Legislative Action Center](#).

Take Action on the Star Act

[Contact](#) your Member of Congress and ask them to support the STAR Act.



Take Action on PCHETA

[Contact](#) your Member of Congress and ask them to urge House Energy & Commerce Committee Chairman Fred Upton and Ranking Member Frank Pallone to hold a mark-up on the Palliative Care and Hospice Education and Training Act (PCHETA, H.R. 3119).

2017 NIWI Scholarships Available

The Nurses in Washington Internship (NIWI) program provides pediatric hematology/oncology nurses with the opportunity to learn how to influence health care through legislative and regulatory processes. The NIWI program will take place March 12-14, 2017 in Washington, D.C. Applications are now available on the [APHON website](#) and are due January 9, 2017.

To learn more visit the [NIWI website](#).

APHON Supports Distinguishing CNSs as APRNs

APHON joined other nursing organizations in a [letter](#) to the Standard Occupational Classification Policy Committee urging them to reconsider the request to exclude the Clinical Nurse Specialist (CNS) from the broad occupation group Registered Nurses (RNs), and to include the CNS as a broad occupation and detailed occupation in the 2018 Standard Occupational Classification.

APHON Supports House & Senate Nursing Workforce Funding Request

APHON joined members of the Nursing Community coalition in urging [House](#) and [Senate](#) Appropriations Chairs and Ranking Members of the full Committee and LHHS Subcommittee to support the coalition's FY 2017 funding request.

House Childhood Cancer Caucus Holds Annual Summit

On September 23, 2016 Advocacy Committee Chair, Beth Siever, attended the 2016 Childhood Cancer Summit hosted by the House Childhood Cancer Caucus. Representatives Michael McCaul, Chris Van Hollen, and Jackie Speier welcomed attendees and provided the following accomplishments:

- Creating Hope (Advancing Hope) Act-Extended for an additional three months

- Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act- Representative Fred Upton has committed to hold hearing when Congress returns from recess in November
- Appropriations-\$30 million included in the Department of Defense Congressionally Directed Medical Research Program's budget for a Peer-Reviewed Young Adult, Adolescent and Pediatric Cancer Research Program.
- Race for Children's Act-Establishes a program under FDA to require Pediatric Research Equity Act (PREA) pediatric studies when a molecular target of an adult cancer drug is relevant to a children's cancer. It would also end the orphan exemption for PREA studies
- New co-chairs of the caucus include Representatives Mike Kelly and GK Butterfield

Greg Simon, Executive Director, Cancer Moonshot Task Force and Douglas Lowy, M.D. Acting Director National Cancer Institute provided an in-depth discussion on how the current legislative landscape is impacting the work of NCI.

White House Holds Briefing on National Childhood Cancer Awareness Month

On September 16th, 2016, Advocacy Committee Chair Beth Siever attended a briefing from the White House regarding National Childhood Cancer Awareness Month. Speakers included Fae Jencks Senior Policy Advisor for Public Engagement, Office of Science and Technology Policy; Dr. Doug Lowy, Acting Director National Cancer Institute; and Dr. Danielle Carnival, Chief of Staff and senior Policy Director, White House Cancer Moonshot Task Force.

Dr. Lowy provided a NCI pediatric cancer overview. Items discussed included NCI experimental therapeutics program (provides support for and priority to pediatric cancer research), 2017 launch of the Pediatric MATCH (Molecular Analysis for Therapy Choice) Trials; Cancer Moonshot and role of NCI, and other priorities and recommendations as related to pediatric cancer research.

Dr. Carnival provided a more in-depth discussion of the Cancer Moonshot timeline and status.

Coalition for Clinical Trials Awareness Hosts Policy Roundtable Discussion

On September 7th, 2016 the Coalition for Clinical Trials Awareness (CCTA) hosted a Policy Roundtable Discussion examining the potential and challenges of making clinical trials opportunities for all age groups and diseases a standard part of patient care. CCTA wants to increase clinical trial participation by fostering support among policy makers, health care provider and the media for greater public awareness about clinical trials. The goal is for a federally sponsored public awareness campaign so that clinical trials enroll more patients, resulting in faster, less expensive access to new medications.

Panelists including David Charles, MD, Chief Medical Officer of the Vanderbilt University Medical Center Clinical Neurosciences Institute & Alliance for Patient Access; Robert Popovian, PharmD, MS, Senior Director, US Government Relations at Pfizer Inc.; and Marcie Reeder, MPH Executive Director National Comprehensive Cancer Network Foundation discussed the following points:

- Lack of information provided to patients regarding clinical trials
- Lack of knowledge by community physicians regarding clinical trial opportunities
- The need for the development of tools for patients and physicians to identify trials
- Challenges of clinical trial participation including disclosure of research, travel/access; anxiety and distress in understanding clinical trials as well as a misunderstanding of what a clinical trial is (standard of care vs. research)
- Timing of talking to patients about clinical trials.

Cancer Landscape Report Released

The American Cancer Society and Alliance for Childhood Cancer released a joint report entitled [*"Translating Discovery into Cures for Children with Cancer: Childhood Cancer Research Landscape*](#)

[Report.](#) The report compiles the latest information related to pediatric cancer, including statistics and trends, a current list of drugs used to treat pediatric cancers, ongoing pediatric cancer clinical trials, and research funding levels.

Pediatric Priority Review Voucher Program Reauthorized

The Pediatric Priority Review Voucher Program was created in 2012 through the Federal Food, Drug, and Cosmetic Act. Under the program, a sponsor who receives an approval for a drug or biologic for a "rare pediatric disease" may qualify for a voucher that can be redeemed to receive a priority review of a subsequent marketing application for a different product. The law placed limitations on the program by stipulating that one year after the third pediatric voucher is awarded, no other pediatric vouchers may be awarded.

On September 30, 2016 President Obama signed the [Advancing Hope Act](#) into law which reauthorized the pediatric priority review voucher program until December 31. This gives Congress time during the Lame Duck session to work out a long term reauthorization for the program.

The Advancing Hope Act extends the program by removing the provision terminating the program one year after the FDA's issuance of three rare pediatric disease vouchers. The law also expands the original priority voucher program by amending the definition of "pediatric rare disease" to focus on disease burden rather than on disease prevalence.

Cancer Moonshot Initiative

On October 17, 2016 Vice President Joe Biden delivered the Cancer Moonshot report to the President. You can find the full reports below as well as a piece by Critical Mass on takeaways for the AYA population:

[Cancer Moonshot Task Force Report](#)

[Vice President's Report to the President](#)

[Cancer Moonshot Blue Ribbon Panel Report](#)

[Top Five AYA Takeaways from the VP's Moonshot Report](#)

VP Biden discussed the Moonshot's trajectory via a strategic plan that places emphasis on the following areas:

1. Realigning the Incentives in the research system
2. Enhancing prevention and screening efforts
3. Engaging patients as partners in research
4. Expanding access to care
5. Creating new financial models to improve development of and access to new therapies while addressing the Issue of rising drug prices

As we near the end of the Obama Presidency many are left wondering what will become of the Cancer Moonshot Initiative once President Obama leaves office. Whether or not the program will remain in its current form is unclear, but there are legislative and regulatory initiatives underway that can serve as the vehicle to drive some of the Moonshot's initiatives. On the regulatory side, agencies have already been participating in ongoing initiatives to fulfill the spirit of the Moonshot such as the U.S. Patent and Trademark Office who is working to increase the incentives for investing in new treatments by improving the quality and clarity of patents issued so that companies have more confidence in their intellectual property right. All of this points to the Cancer Moonshot living on in some form or fashion at the intersection of public interest and political will.

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