



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.

****September is Childhood Cancer Awareness Month; Send you health policy and advocacy news to Jordan at jwildermuth@connect2amc.com.***

If it Looks Like a Duck and Quacks Like a Duck...

Congress returned from their Summer Recess on September 8th. The major deadline looming is the end of the Federal fiscal year on September 30th. Congress passed a \$1 Trillion stop-gap spending bill (Continuing Resolution or CR) that will fund the Federal government until December 11, 2014. Congress returns to their districts for the mid-term elections which will be held on November 4, 2014. Congress will then have to return to Washington after the elections to pass another CR to continue to fund the Federal government after the current CR expires on December 11, 2014.

Do not expect any big votes occurring between now and the end of the year as Members of Congress are preparing for the midterm elections and the ensuing "lame-duck" session in which Congress meets after its successor is elected, but before the successor's term begins. The speculation is focused around the possibility of Republicans gaining control of the Senate, leading to Republican control of both chambers. The answers will reveal themselves in November!

NIWI Scholarships

APHON is committed to being influential in decision-making affecting the care for children, adolescents, and young adults with cancer and other blood disorders and in that spirit we will be awarding two scholarships for the [Nurses in Washington Internship Program](#) (NIWI) March 15-17, 2015. NIWI provides nurses with the opportunity to learn how to influence health care through the legislative and regulatory processes. Applications will be available in October-stay tuned for more information.

APHON Supports Request for Prioritization of Research Items

APHON signed onto a [letter](#) from the Alliance for Childhood Cancer requesting a meeting with the National Cancer Institute to discuss ways in which to better communicate and develop a plan to prioritize and implement proposals for pediatric oncology research and drug development.

APHON Supports VHA Handbook Update

APHON signed on to a letter from the ANSR Alliance to Acting Secretary of Veterans Affairs Sloan D. Gibson in support of the modernization of the Veterans Health Administration's (VHA) Nursing Handbook, which includes the recognition of Advanced Practice Registered Nurses (APRNs) as full practice providers when providing care in a VA facility. As stated in the letter, The VHA's recommendation to acknowledge full practice authority for APRNs supports the profession to practice to the full extent of APRN education and training and will help ensure an adequate supply of health providers are available to care for the veteran population served by the VA.

Alliance for Childhood Cancer Action Day

APHON sponsored the Alliance for Childhood Cancer Action Day on June 23-24, 2014, which brought over 250 advocates from 32 states together for over 180 meetings with members of Congress and their staff. As a result of this advocacy, 16 additional Members of Congress have become cosponsors of the Caroline Pryce Walker Conquer Childhood Cancer Reauthorization Act.

Step Up Campaign

APHON has been participating in the [Step Up Campaign](#), which is a coordinated community campaign that allows individuals and organizations to work together to highlight and educate decision makers and the general public about the crucial need for increased childhood cancer funding. Organizations take part through targeted social media outreach as well as events such as the Rally for Medical Research (September 18-call on our nation's policymakers to make funding for National Institutes of Health (NIH) a national priority), the Congressional Cancer Caucus, and CureFest (September 20-welcome all families to Washington D.C. and giving parents and children impacted by childhood cancer an extra opportunity to connect in person with others who are in a similar situation). For more information visit the [Coalition Against Childhood Cancer](#).

APHON Members Attend Pediatric Cancer Summit and Briefing

On September 19, 2014, APHON members Beth Siever and Kara Bryant attended a Pediatric Cancer Summit hosted by the Congressional Childhood Cancer Caucus and titled: Pediatric Cancer Major Advances, Major Challenges. The Summit was attended by congressional members, legislative aids, advocates (parents, patients, and health care professional). Dr. Francis Collins, Director of the National Institutes of Health was the keynote speaker.

In the afternoon, Beth was able to attend a briefing and discussion with pediatric cancer advocates at the White House Eisenhower Executive office Building. At the briefing the National Cancer Institute introduced a new program for pediatric cancer research, the MATCH Program, which has a launch date of January 2015 (Stay tuned). Also announced was the Office of Management and Budget's plan to begin tracking data in 2015-2016 on how much money is actually spent on pediatric cancer research.

On September 20, 2014, Kara attended a White House tour with families and advocates and then a Childhood Cancer Roundtable Policy Discussion. From an advocacy perspective this was a historic event- having all the different advocacy groups gather together with the opportunity to hear and address Members of Congress, directors, and the White House administration.

Meeting of the Pediatric Advisory Committee

On September 10, 2014, the FDA hosted “Under the Microscope: Pediatric Drug Development,” a meeting explore and discuss challenges related to pediatric drug development. You can find a summary of the meeting published by The FDA Law Blog [here](#).

Meeting of the National Cancer Institute (NCI) Council of Research Advocates

The NCI Council of Research Advocates will hold a meeting on October 21, 2014 to provide an update from the NCI and discuss how advocates can advance cancer immunotherapy research.

Oncology Nursing Society (ONS) Hosts Palliative Care Briefing

On September 18, 2014 ONS hosted a briefing on Capitol Hill providing an overview of emerging trends in palliative care and the role of oncology nurses in the palliative care team. The Patient Centered Quality Care for Life Act (HR 1666) was also reviewed during the briefing. This legislation creates a patient-centered quality of care initiative for seriously ill patients through the establishment of a stakeholder strategic summit, quality of life education and awareness initiative, health care workforce training, an advisory committee, and palliative care focused research, and for other purposes.

21st Century Cures Initiative

Representative Fred Upton (R-MI) and Representative Diana DeGette (D-CO), in collaboration with the House Energy and Commerce Committee, launched the 21st Century Cures Initiative to place an emphasis on the discovery, development, and delivery of new treatments and cures for rare diseases. To accomplish this, experts in the field have been solicited to contribute to white papers, hearings, and forums to address gaps between advances in scientific knowledge about cures and the policies that regulate them. The committee is seeking ongoing input on this initiative and any comments can be sent to cures@mail.house.gov. More information can be found [here](#).

On September 10, 2014, a 21st Century Cures Initiative roundtable discussion was convened by Rep. Upton and Rep. DeGette with an emphasis on examining what can be done legislatively to move new therapies faster. Discussion was centered on encouraging participation in research, facilitating scientific collaboration, and reducing administrative burden. One item was removing barriers to participation in clinical trials. Currently the consent form is 40 pages long which dissuade people from participating in the trials and the presence of such barriers leads young investigators to look elsewhere for research opportunities.

Robust conversation was also held on the role of the patient. The buzz words in health care are patient-centered and outcome-focused. A question was raised about what current activities are occurring that promote patient engagement. Secretary Hamburg from the FDA stated that patient reported outcomes are being used in product development and that patient need is shaping the development of clinical trials and data collection. There also ample opportunities for patients to serve on advisory panels within the agency.

The Creating Hope Act Lives Up to Its Name

In 2012, Congress passed the Creating Hope Act which created incentives for companies to pursue treatments tailored specifically for children. Under the Act, a program was created that would provide a voucher any company that developed a drug specifically to treat a rare pediatric disease, including pediatric cancer. The voucher entitles the holder to a faster review of another drug by the FDA which the company could then use or sell.

On July 30, 2014, BioMarin was the first company to receive a voucher, which they sold for \$67.5 million. This has garnered attention from other companies that are now interested in investing in pediatric drug development-creating HOPE for kids with cancer!

Congressional Briefing Held on Sickle Cell Disease

On September 16, 2014 the American Society for Hematology (ASH) co-hosted a briefing on Capitol Hill to highlight the need for state-of-the-art clinical care for SCD patients. The briefing was held in conjunction with ASH's endorsement of a new [NHLBI Report on Sickle Cell Disease](#).

How the Food and Drug Administration Safety and Innovation Act (FDASIA) Helps Children with Rare Diseases

In 2012 the Food and Drug Administration Safety and Innovation Act (FDASIA) was enacted. An important component of the law was the direction to the FDA to hold a meeting with stakeholders and discuss ways to encourage and accelerate the development of new therapies for pediatric rare diseases, and issue a report that includes a strategic plan for achieving this goal. In July 2014, the *Report: Complex Issues in Developing Drugs and Biological Products for Rare Diseases and Accelerating the Development of Therapies for Pediatric Rare Diseases* was published. The four objectives of the report are:

1. Enhance foundational and translational science for pediatric rare diseases;
2. Strengthen communication, collaboration, and partnering for pediatric rare diseases within and outside FDA;
3. Advance the use of regulatory science to aid clinical trial design and performance for pediatric rare diseases; and
4. Enhance FDA's review process for pediatric rare disease products.

Overall, the message that APHON members can take away is that there are many challenges to developing new therapies for pediatric rare diseases, but pediatric hematology/oncology nurses play a key role in recognizing and including patients, families, and caregivers throughout the development process.

Supporting Pain Management in Cancer Patients

The Pain and Policy Studies Group at the University of Wisconsin School of Medicine and Public Health Carbone Cancer Center released a new report entitled *Achieving Balance in State Pain Policy: A Progress Report Card (CY 2013)*. In the United States there continues to be two trends in pain management- the medical under-treatment of pain and the non-medical use of controlled substances. The report highlights improvements made in the regulation of pain management across patient populations including cancer patients. The impetus of the report is to ensure that a balance is achieved in the use of medications that are used for pain relief but can also be abused. View the full report [here](#).

Issues and Legislation of Interest

Below are bills that have been introduced during the current Congress that have an impact either on pediatric hematology/oncology nurses or our patients.

Access

S. 1879 Cancer Treatment Parity Act of 2013

Requires a group or individual health plan providing benefits with respect to anticancer medications administered by a health care provider to provide no less favorable coverage for prescribed, patient-administered anticancer medications

H.R. 1801 Cancer Drug Coverage Parity Act

Requires a group or individual health plan providing benefits with respect to anticancer medications administered by a health care provider to provide no less favorable coverage for prescribed, patient-administered anticancer medications

H.R. 1416 Cancer Patient Protection Act of 2013

Requires the budgetary resources sequestered for payments for drugs and biologicals under Medicare be available for obligation for drugs and biologicals furnished on or after enactment of this Act in the same amount and manner as if such order had not been issued.

H.R. 1666 Patient Centered Quality Care for Life Act

Creates a patient-centered quality of care initiative for seriously ill patients through the establishment of a stakeholder strategic summit, quality of life education and awareness initiative, health care workforce training, an advisory committee, and palliative care focused research, and for other purposes.

Research/Clinical Trials

S. 424 National Pediatric Research Network Act of 2013

Provides for the establishment of a National Pediatric Research Network.

S. 1247/H.R. 2058 Pediatric, Adolescent, and Young Adult Cancer Survivorship Research and Quality of Life Act of 2013

Make grants to eligible entities to establish pilot programs to develop, study, or evaluate model systems for monitoring and caring for childhood cancer survivors.

S. 1251/H.R. 2607 Caroline Pryce Walker Conquer Childhood Cancer Reauthorization Act

Reauthorizes through FY2018 cancer research programs

H.R. 225 National Pediatric Research Network Act of 2013

Provides for the establishment of a National Pediatric Research Network.

H.R. 2301 Clinical Trial Cancer Mission 2020 Act

Revises clinical trial registry data bank provisions of the Public Health Service Act to include a device or drug clinical trial whether or not it results in a positive or negative outcome.

Workforce

S. 739/H.R. 1907 National Nursing Shortage Reform and Patient Advocacy Act

Requires hospitals to implement a staffing plan that includes a minimum direct care registered nurse-to-patient ratio by unit and development of a national acuity tool.

H.R. 1821 Registered Nurse Safe Staffing Act of 2013

Requires each Medicare participating hospital to implement a hospital-wide staffing plan for nursing services furnished in the hospital.

H.R. 2986 Protecting Access to Primary Care Act

Extends to nurse practitioners, physician assistants, clinical nurse specialists, and certified nurse midwives payment for primary care services furnished in 2013 and 2014 at a rate not less than 100% of the Medicare payment rate applicable to physician for such services.

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