



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.

****In case you missed it-May 4-12 was National Nurses Week, thank you for all you do! Send your health policy and advocacy news to Jordan at jwildermuth@aphon.org.***

Congressional Action at Last

On April 16, 2015 President Obama signed into law the Medicare Access and CHIP Reauthorization Act of 2015 which repealed the Sustainable Growth Rate (SGR), and more importantly for APHON, extends the Children's Health Insurance Program (CHIP) for two years. Repeal of the SGR has been an ongoing issue for years as Congress has passed 17 short term patches meant to stave off cuts to reimbursement for physicians. The fear was that if rates were cut there would be no incentive for physicians to treat Medicare beneficiaries.

With SGR repeal checked off, Congress now has a free hand to tackle other larger scale health care issues gaining traction such as the Precision Medicine Initiative (PMI) and the 21st Century Cures Act. The National Institutes of Health (NIH) has pulled together a team of experts in precision medicine and large clinical research studies that will seek public input from stakeholders that will help articulate the vision for building a national participant group for the PMI and help define what issues will need to be addressed and considered as part of the study design and what success would look like five and 10 years out. A preliminary report will be delivered in September 2015 that will inform efforts to accelerate the understanding of individual differences that play a role in health, with the goal of informing better prevention and treatment strategies tailored for each person. As you will read more about in this issue, the 21st Century Cures Act also seems to be attracting the attention from those once solely concentrated on SGR repeal. Being a broad and all-encompassing bill, many conversations and debates are currently being held. The balance that is trying to be struck is one of accelerating development and innovation while maintaining safety and efficacy and a bill that does not favor one interest over another.

The question on people's minds is whether this attitude of bipartisanship will remain or if the 2016 presidential election cycle will slowly creep into the legislative process. Whatever the case may be, there are numerous health care issues taking shape that address the overall healthcare delivery system. Please remember to share your experiences and thoughts with your policy-makers and APHON to ensure practical and sound policies are made that impact the lives of children and young adolescents with cancer.

Childhood Cancer STAR Act and Childhood Cancer Day

On June 15, Congressmen Michael McCaul (R-TX) and Chris Van Hollen (D-MD) and Senators Jack Reed (D-RI) and John Isakson (R-GA) introduced the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act. The legislation expands child, adolescent and young adult cancer research, develops model systems to help improve survivors' care, improves tracking of cancer incidences and identifies opportunities to expand the development of therapeutics for childhood cancers.

The introduction of the STAR Act corresponded with the fourth annual Childhood Cancer Action Days which is organized by the Alliance for Childhood Cancer and brings patients, families, survivors, advocates, and other stakeholders to Capitol Hill to address childhood cancer issues such as improved research and treatments. This year there were almost 300 advocates in attendance asking for support of the STAR Act and also for \$33 billion in funding for the National Institutes of Health in Fiscal Year 2016 (specifically increase funding for the National Cancer Institute to \$5.4 billion).

APHON's membership in the Alliance for Childhood Cancer helps support initiatives such as the STAR ACT (which is a product of the childhood cancer policy roundtables that APHON was a part of) and the Childhood Cancer Action Days.

APHON Sends Letter to USP

As a follow-up to the to the Safe Handling of Hazardous Drugs Association Stakeholders meeting hosted by the Oncology Nursing Society (ONS) and attended by APHON member, Kristin Belderson, DNP MS RN CPON in February, APHON has endorsed the position statement from ONS/ASCO/HOPA entitled [Ensuring Healthcare Worker Safety When Handling Hazardous Drugs](#). APHON also sent a separate letter to the U.S. Pharmacopeial Convention highlighting our support of enhancing workplace safety but outlining concerns with revisions to the General Chapter Hazardous Drugs—Handling in Healthcare Settings, specifically other healthcare professionals, especially those not working in oncology, who are now working with hazardous drugs and often have not had the benefit of safety precautions. APHON raised questions about who will be educating the non-oncology nurses and ancillary staff on General Chapter as well as who will be monitoring the safety of non-oncology health care providers. APHON suggested that USP reach out to other stakeholders and professional associations, such as ANA (American Nurses Association) to obtain their knowledge and support of the standards.

APHON Submits Comments on 21st Century Cures Act

APHON sent [comments](#) to the House Energy and Commerce Committee in support of the 21st Century Cures Act and specifically calling for the inclusion of pediatric hematology/oncology nurses in certain provisions as well as the reauthorization of the Rare Pediatric Disease Priority Review Voucher Program.

Alliance for Childhood Cancer Sends Comments on 21st Century Cures Act

APHON joined with members of the Alliance for Childhood Cancer in providing [comments](#) to the House Energy and Commerce Committee on proposals within the 21st Century Cures legislation that will affect

research and care for children with cancer.

APHON Endorses the Advancing Hope Act and the Kids' Innovative Drugs Initiative

APHON has joined with other organizations in [endorsing](#) both the Advancing Hope Act and the Kids' Innovative Drugs Initiative (KIDS). The Advancing Hope Act permanently reauthorizes the Creating Hope Act to continue the program of pediatric priority review vouchers as an incentive for pediatric rare disease drug development. KIDS would provide access to unapproved and abandoned adult drugs through reforms to the Pediatric Research Equity Act (PREA) and the Best Pharmaceuticals for Children Act (BPCA).

APHON Signs on to Funding Requests for NCI and NIH

APHON joined with members of the Alliance for Childhood Cancer in [thanking](#) co-chairs of the Childhood Cancer Caucus, Representatives Michael McCaul (R-TX) and Chris Van Hollen (D-MD) for their support. The Alliance also outlined funding priorities and specific requests for report language related to childhood cancer.

APHON Member Recognized for Receiving NIWI Scholarship

The University of Alabama at Birmingham (UAB) School of Nursing [recognized](#) alumna Courtney Hahn Sullivan for receiving one of two NIWI scholarships provided by APHON in 2015. Once again congratulations to Courtney and Beth Savage on receiving the scholarships and for representing APHON on Capitol Hill.

First World Health Assembly Event on the Global Challenges of Childhood Cancer

During the 68th World Health Assembly (WHA) held on May 18, 2015, the first WHA event on the global challenges of childhood cancer was convened. The event provided a forum for the Ministers of Health from the Russian Federation, the Federal Republic of Germany, the Republic of Ghana and the Republic of the Philippines to discuss and share progress in the implementation of best practices and models that have improved access to care and reduced childhood cancer mortality and morbidity. The panelists recommended solutions to overcome barriers that limit access to affordable care and services for children with cancer and survivors of childhood cancer.

WHA is the highest decision making body of the World Health Organization (WHO) and the world's highest health policy making body. It is attended by delegations from all 194 WHO Member States as well as representatives from other international development organizations and civil society organizations. For more information visit the [American Childhood Cancer Organization](#) (ACCO).

Legislative Reauthorizing Title VIII Introduced

A provision of the Public Health Services Act is Title VIII which includes nursing workforce development programs carried out by the Health Resources and Services Administration (HRSA). These programs

provide the largest source of federal funding for nursing education, offering financial support for nursing education programs, individual students, and nurses. In order for a program to be implemented it needs to be *authorized* through legislation. Once authorized, the program can then be allocated money through the appropriations process (much like our budgeting process at work or at home). One thing to remember is that just because something has been authorized does not mean that money will be allocated. Additionally, if the authorization expires, money could still be allocated to the program but it would be at the mercy of the appropriators as the line item in the budget would be gone.

Authorizations generally last for a period of between two and five years. Title VIII was reauthorized with the passage of the Affordable Care Act in 2010 for a period of five years which means that it needs to be reauthorized for funding this year. Rep. Lois Capps (D-CA) and Rep. David Joyce (R-OH) have reintroduced the *Title VIII Reauthorization Act* and APHON has joined with other nursing organizations in support. Title VIII has been in existence for over 50 years and policy-makers understand the importance of these programs.

Legislation Could Affect Nurse's Work Week

The Save American Workers Act of 2015 (H.R. 30/S. 30) revises the definition of a full-time employee as a person who averages at least 40 hours of service per week rather than someone who averages 30 hours per week. Typically, Registered Nurses who work in a hospital setting work a three day, 12 hour shift, with a workweek of 36 hours. If this legislation is passed, employers would not have to offer health insurance benefits to anyone who works less than 40 hours per week. If you would like to contact your Member of Congress and share how this legislation would impact your work situation you can find contact information for them via the [House](#) and [Senate](#) website. You can also submit your story through the [American Nurses Association](#). More information on the bill is available from the [Oncology Nursing Society](#).

Childhood Cancer Policy Roundtable

APHON continues to be involved with the Childhood Cancer Policy Roundtable and is represented by Beth Siever and Kara Bryant. The three workgroups that were previously discussed in the *Winter Advocacy Correspondent* (Maximizing Discovery Through Research; Accelerating Development & Availability of Promising Treatments; and Maximizing Delivery: Care, Quality of Life, Survivorship, and Caregiver Support) have been working to further sharpen the goals agreed upon by the whole group and have developed draft work plans outlining timelines, sub-goals and possible action steps for consideration.

Workgroup Goals:

Accelerating Development & Availability of Promising Treatments, and Maximizing Delivery

- Explore Modifications to Best Pharmaceuticals for Children Act (BPCA) and Pediatric Research Equity Act (PREA) to Optimize Effectiveness for Pediatric Cancer
- Engage in Ongoing Congressional FDA Reform Initiative Where Important for Childhood Cancer

Maximizing Delivery: Care, Quality of Life, Survivorship, and Caregiver Support

- Align with other coalitions working within the Care, Quality of Life, Survivorship, and Caregiver

- space on legislation
- Explore access and payment gap issues and policy options across the entire range of the pediatric cancer experience
- Hold federal agencies accountable for improving access and coverage across the entire range of the pediatric cancer experience, especially after end of treatment
- Explore access and payment gap issues and administrative options across the entire range of the pediatric cancer experience

Maximizing Discovery through Research

- Increase childhood cancer research funding
- Pediatric Cancer Use of FY 15 Gabriella Miller Kids First Research Act Funding
- Increase Effectiveness of Agencies as Funders and as Partners

APHON will inform members about any action items to be taken as a result of this work.

Adamson Named to National Cancer Advisory Board

Dr. Peter Adamson, attending Physician in the Division of Oncology at The Children's Hospital of Philadelphia (CHOP) has been named by President Obama to the National Cancer Advisory Board.

Call for Nominations

The National Cancer Institute (NCI) is pleased to invite nominations for membership on the NCI Council of Research Advocates (NCRA) starting in June 2015. The NCRA is NCI's only federal advisory board composed of advocate community leaders. The NCRA focuses on facilitating research and identifying and responding to challenges facing the Institute at the request of NCI leadership. To learn more about the NCRA, including a roster of current members and information on past meetings, visit [here](#).

- An explanation of the roles and responsibilities of research advocates at NCI
 - A description of the value of advocacy in cancer research
 - Information on how to become a research advocate at NCI
-

Status of Cancer Report Released

The latest Annual Report to the Nation on the Status of Cancer, 1975-2011 (ARN) is now available, key highlights and the full report can be found [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. 298/H.R. 546](#) *Advancing Care for Exceptional Kids Act*

Amends titles XIX and XXI of the Social Security Act to provide States with the option of providing services to children with medically complex conditions under the Medicaid program and Children's Health Insurance Program through a care coordination program focused on improving health outcomes for children with medically complex conditions and lowering costs, and for other purposes.

[H.R. 700/S. 428](#) *Stabilize Medicaid and CHIP Coverage Act*

Amends titles XIX and XXI of the Social Security Act to provide for 12-month continuous enrollment of individuals under the Medicaid program and Children's Health Insurance Program, and for other purposes.

[H.R. 1537](#) *Advancing Hope Act of 2015*

Amends the Federal Food, Drug, and Cosmetic Act to reauthorize a program of priority review to encourage treatments for rare pediatric diseases, and for other purposes.

[H.R. 2739/S. 1566](#) *Cancer Drug Coverage Parity Act of 2015*

Amends the Public Health Service Act to require group and individual health insurance coverage and group health plans to provide for coverage of oral anticancer drugs on terms no less favorable than the coverage provided for anticancer medications administered by a health care provider.

Research/Clinical Trials

[H.R. 531/S. 318](#) *Accelerating Biomedical Research Act*

Prioritizes funding for the National Institutes of Health to discover treatments and cures, to maintain global leadership in medical innovation, and to restore the purchasing power the NIH had after the historic doubling campaign that ended in fiscal year 2003.

[H.R. 744](#) *Medical Innovation Act of 2015*

Authorizes the collection of supplemental payments to increase congressional investments in medical research, and for other purposes.

[H.R. 6](#) *21st Century Cures Act*

To accelerate the discovery, development, and delivery of 21st century cures, and for other purposes.

[S. 1421/H.R. 971](#) *Orphan Product Extensions Now Accelerating Cures and Treatments Act of 2015*

A bill to amend the Federal Food, Drug, and Cosmetic Act to authorize a 6-month extension of certain exclusivity periods in the case of approved drugs that are subsequently approved for a new indication to prevent, diagnose, or treat a rare disease or condition, and for other purposes.

[H.R. 2548](#) *Pediatric Research Improvement Act of 2015*

Amends the Public Health Service Act with respect to a national pediatric research network.

[H.R. 2447](#) *To amend the Public Health Service Act to provide for an NIH research strategic plan*

Amends the Public Health Service Act to provide for an NIH research strategic plan.

Other

[H.Res. 102](#) *Expressing support for designation of September 25, 2015, as “National Pediatric Bone Cancer Awareness Day”*

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