



## The APHON Advocacy Correspondent

Welcome to the first issue of the Advocacy Correspondent! This new member benefit is 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.

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### Glossary

Just as nurses have their own jargon, lobbyists and politicians also speak in their own tongue. Some people might assert that this is meant to simply confuse the American public but as former Yale President Kingman Brewster stated, “Incomprehensible jargon is the hallmark of a profession.” Here are some common terms that are used when discussing policy and advocacy.

*Advocacy-* While all lobbying is advocacy, not all advocacy is lobbying. Advocacy is any action that speaks in favor of, recommends, argues for a cause, supports or defends, or pleads on behalf of others. It includes public education, regulatory work, litigation, and work before administrative bodies, lobbying, voter registration, voter education, and more.

*Administrative Advocacy-* Efforts to influence actions of the Executive Branch, such as by commenting on rulemakings and regulations, Executive Orders, and other policies.

*Amendment-* A proposal to alter the text of a pending bill or other measure by striking out some language, by inserting new language, or by both striking out and inserting new language. An amendment can be offered in committee or on the floor of the House or Senate.

*Appropriation-* Legislation to provide the money required to fund governmental departments, agencies, and programs previously established by authorizing legislation.

*Authorization-* Legislation to establish a proposed governmental program (such as Title VIII). Authorizations may be for a specified amount of money or an indefinite amount, but do not actually provide any money.

*Bill-* A proposed law introduced in either chamber of Congress.

*CMS-* Center for Medicare and Medicaid Services

*Coalition-* usually a group of two or more organizations that are working together jointly on a specific

issue or cause.

*Discretionary Spending*- Spending on Federal programs other than defense-related activities.

*HHS*-The U.S. Department of Health and Human Services

*Legislative Advocacy*- Efforts to change policy through the legislative branch of government such as Congress. This may include lobbying in support or opposition to a bill, the crafting of new legislative language, writing amendments to existing bills, or encouraging others to contact their legislators. Not all legislative advocacy is lobbying.

*Lobbying*- The process of trying to influence legislators or other officials to vote for or against a piece of legislation or not take an official action.

*Reauthorization*- The process by which legislation is renewed for a specified number of years.

*Regulation*-A rule or order that has the force of law that originates from the executive branch (usually from an agency), and deals with the specifics of a program. Congress, for example, instructed HHS to develop a health-care exchange but HHS must develop regulations to reach this goal.

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## APHON Members Attend Nurses in Washington Internship Program

APHON President Jami Gattuso, MSN RN CPON® and past Director-at-Large, Beth Siever, MSN RN CPNP CPON® both attended the Nurses in Washington Internship Program (NIWI) March 30-April 1 2014. NIWI is open to any RN or nursing student (all levels of education) that is interested in an orientation to the legislative process. Specifically, the program emphasizes how nurses can be involved and influence policy at the local and national level through workshops and panel discussions and culminating with visits on Capitol Hill. NIWI is sponsored by the Nursing Organizational Alliance which is comprised of over 60 nursing organizations (including APHON) with the mission of providing a forum for identification, education and collaboration building on issues of common interest to advance the nursing profession.

To learn more about NIWI visit the Nursing Organizational Alliance [website](#).

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## Funding

The appropriations process for Fiscal Year (FY) 2015 is currently underway and legislative committees are holding hearings and marking up the legislation that will set levels for discretionary spending as well as set allocations for specific programs including programs that address nurse education and the nursing workforce. On June 10, the Senate Appropriations Subcommittee on the Departments of Labor, Health and Human Services, and Education, and Related Agencies (Labor-HHS-Education) marked up and approved their FY 2015 appropriations bill. This is significant because the Senate LHHHS appropriations bill includes programs that directly impact APHON members such as Title VIII (HRSA) and funding for NIH. Below is a chart that outlines FY 2014 levels of funding compared to what the LHHHS subcommittee approved for FY 2015.

Program	FY 2014	FY 2015 Senate	Percentage
Nursing Programs (Title VIII-HRSA Nursing Workforce Development Programs)	\$223.3 Million	\$236.3 Million	1% Increase
National Cancer Institute	\$4.9 Billion	\$5 Billion	0.8% Increase
National Institute of Nursing Research	\$140 Million	\$142.2 Million	1% Increase

APHON belongs to [The Americans for Nursing Shortage Relief \(ANSR\) Alliance](#) which represents a diverse cross-section of health care and other related organizations, health care providers, and supporters of nursing issues and has united to address the national nursing shortage and the delivery of high quality nursing care to the nation. Together, ANSR advocates on behalf of funding for such things as Title VIII (Nursing Workforce Development Programs-HRSA) and Nurse Managed Health Clinics. The following are “asks” that ANSR has given to Congress for FY 2015 funding levels:

- \$251 million for Title VIII Nursing Workforce Development programs
- \$20 million for Nurse Managed Health Clinics to increase access to primary care for thousands of uninsured people in rural and underserved urban communities.

You can ask your member of Congress to support these requests by contacting them via email or telephone. Don't know who your member of Congress is? No problem! Click [here](#) to find your member.

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### Complex Issues in Developing Drug and Biological Products for Rare Diseases

The FDA posted a Federal Register notice for comments in conjunction with a public workshop on Complex Issues in Developing Drug and biological Products for Rare Diseases. The intent of the comments and the workshop is to discuss ways to encourage and accelerate the development of new medical devices and therapies for pediatric rare diseases. APHON signed on to [comments](#) submitted by the Alliance for Childhood Cancer which identified the following areas that FDA should consider:

1. Continue flexible approach in addressing risk-benefit for pediatric cancer drug development.
  2. Prioritize enhanced pediatric cancer clinical trial endpoints development.
  3. The FDA should work with a broad range of stakeholders including industry and patient advocacy groups to determine where harmony is needed between FDA and European Medicines Agency (EMA) policy regarding pediatric drug development plans as well as other incentives and requirements.
  4. Amend the Pediatric Research Equity Act to include a special rule for oncology drugs (the law requires the conduct of pediatric studies for certain drug and biological products).
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### Health Resources and Services Administration Announces New Bureau

The Health Resources and Services Administration (HRSA) announced that it has created a new bureau that will be referred to as the Bureau of Health Workforce. Currently, health workforce programs are housed within different bureaus and the realignment within HRSA will bring together these key programs in one designated bureau. The new design will enable HRSA to better achieve its mission and respond to the needs of the health workforce including the supply, distribution, and retaining of health professionals.

Over \$1 billion has been appropriated for the new bureau which will house over 40 health workforce programs. The new bureau will include two offices, the Office of Workforce Development and Analysis (grants, research) and the Office of Health Careers (scholarship & loan repayment programs, pipeline programs). Contacts within HRSA and the different programs will remain the same. Rebecca Spitzgo will lead the Bureau of Health Workforce.

The goals of the Bureau of Health Workforce include:

1. Train the next generation of diverse health care providers to serve underserved populations through its grants to health professions schools and training programs.
2. Examine a broad range of issues that impact the supply, demand, distribution, and education of the Nation's health workforce and provide policymakers with the information necessary to make informed decisions regarding the health professions workforce and provision of care.
3. Support graduate medical education.
4. Recruit and retain providers and students to underserved areas through both the National Health Service Corps and NURSE Corps Scholarship and Loan Repayment Programs.
5. Protect the public from health care practitioners, providers, and suppliers with a history of malpractice, adverse actions, fraud and abuse through the National Practitioner Data Bank.

On a conference call held by HRSA on June 4, there were a couple questions raised by various stakeholders that are of interest to APHON. The first was a concern that public health was being overlooked and that the realignment seemed to have a clinical focus. The second was if there would be any effect on the funding distribution. Mary Wakefield, the Administrator of HRSA explained that public health has been integrated across programs and that new programs are being created to provide a lift to the public health perspective. Additionally, there is a focus on the various programs to work within the context of the community and to look at both population and personal health. In response to funding, all funds are driven by the appropriations process through Congress and each program will show up as a line item so there will not be any change to the current distribution of funds.

To contact HRSA with any questions on the new Bureau of Health Workforce you can submit via their Facebook page, <https://www.facebook.com/HHS.HRSA> or email, [ask@hrsa.gov](mailto:ask@hrsa.gov).

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### **New Study from the Institute for Pediatric Nursing**

Findings from the 2011 Institute for Pediatric Nursing survey on [Undergraduate Pediatric Nursing Education: Issues, Challenges and Recommendations](#) was published in March-April 2014 edition of the Journal of Professional Nursing.

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### **Alliance for Childhood Cancer Advocacy Day**

On June 23, APHON helped sponsor the Childhood Cancer Action Day, a two-day event hosted by the Alliance for Childhood Cancer that includes issues and advocacy training and pre-arranged Capitol Hill visits with Congressional Representatives and their staff. APHON is a member of The Alliance, whose goal is to provide the childhood cancer community - parents, children, and others with the opportunity to visit their Representatives on Capitol Hill and advocate for the important childhood cancer issues currently before Congress.

You can take part in the activities by asking your member of Congress to support one or both of these issues:

- Fully funding Childhood Cancer Research: The NCI is investing in a number of large scale, national clinical trials focused on precision medicine for adults with various types of cancers, but has no such research investment for precision medicine for children with cancer. Years of decreased funding to the NCI is directly impacting research conducted for children with cancer throughout the U.S.
- The Caroline Pryce Walker Conquer Childhood Cancer Reauthorization Act: Congress needs

to expand research, support childhood cancer registries, and identify barriers to developing new therapies.

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## Congressional Childhood Cancer Caucus

Did you know that there is a Congressional Caucus dedicated to providing information to members of Congress? Representative Michael McCaul (TX-10) and Representative Chris Van Hollen (MD-8) chair the Childhood Cancer Caucus whose mission is to serve as a clearinghouse for information on pediatric cancer and a forum to aid Members of Congress in working together to address pediatric cancer. You can find out more information on the caucus' [website](#).

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## Congressional Recess Begins August, Plenty of Time to Play

Each year Congress wraps up work in Washington D.C. at the end of July and takes a month-long recess, returning to Hill after Labor Day. During this time, you can find your member of Congress at their district office, hosting town hall meetings, or appearing at various summertime events. This is a perfect time to either schedule a visit with your member of Congress in your hometown or if you see them at an event, introduce yourself and tell them that you are a pediatric hematology/oncology nurse.

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## 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.

### **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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