



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-In the spirit of the 2016 election, [musician](#) urges super-PACs to make a contribution to childhood cancer research! Send your health policy and advocacy news to Jordan at jwildermuth@aphon.org.***

Year in Review

As 2015 comes to a close I am sure that you have seen the many different lists that are released recapping things that were popular or major events that occurred throughout the course of the year. While APHON didn't have any hit songs or make any fashion statements, there were a number of advocacy accomplishments that should be noted that will also continue to lead our efforts into 2016 and beyond.

- Developed a Health Policy and Legislative Agenda
- Joined the Patient Quality of Life Coalition
- Joined the Nursing Community
- Supported the Childhood Cancer STAR Act
- Supported the Palliative Care and Hospice Education and Training Act
- Submitted comments on and supported the 21st Century Cures Act
- Submitted comments on USP General Chapter 800 Hazardous Drugs-Handling in Healthcare Settings
- Gathered over 100 letters at the annual conference that were delivered to Members of Congress in support of the Childhood Cancer STAR Act

2016 will be an even more exciting year as we continue promoting optimal nursing care for children, adolescents, and young adults with cancer and blood disorders, and their families.

Take Action on the STAR Act

There are currently 125 [cosponsors](#) of the STAR Act. Congress heads home for the holidays at the end of this week.

Help us reach a few more offices before 2015 comes to a close by taking action today:

- [Learn more](#) about the STAR Act.
- [Write your Senators and Representative](#).



Take Action on PCHETA

Contact your [Representative](#) and ask them to cosponsor the Palliative Care and Hospice Education and Training Act (H.R. 3119).

PCHETA would expand the palliative care workforce, promote awareness of the benefits of palliative care among patient and providers, and improve the evidence base for this care. APHON has signed on to a [letter of support](#) from the Patient Quality of Life Coalition for this legislation.

Spending Package Includes Great News for Pediatric Cancer

Congress passed a \$1.1 trillion spending package that will fund the government through September 2016. Included in the package is the reauthorization of the Creating Hope Act which provides market incentives to pharmaceutical companies to develop drugs for pediatric rare diseases. Additionally, The Nursing Community has provided the numbers included for nursing workforce development programs:



FY 2016 Proposed Appropriations Levels Compared to FY 2015 Enacted Levels 12/16/2015

PROGRAM	FY 2015 Consolidated and Further Continuing Appropriations Act of 2015 ¹ (12/15/14)	FY 2016 Consolidated Appropriations Act of 2016 ² (12/16/15)	FY 2016 Consolidated Appropriations vs FY 2015 Levels +/- (%)
Nursing Workforce Development Programs (Title VIII)	\$231.622 mil	\$229.472 mil	-\$2.150 mil (-0.93%)
Advanced Education Nursing	\$63.581 mil	\$64.581 mil	+\$1.000 mil (+1.57%)
Nursing Workforce Diversity	\$15.343 mil	\$15.343 mil	level
Nurse Education, Practice, Quality, and Retention	\$39.913 mil	\$39.913 mil	level
NURSE Corps Loan Repayment and Scholarship Programs	\$81.785 mil	\$83.135 mil	+\$1.350 mil (+1.65%)
Nurse Faculty Loan Program	\$26.500 mil	\$26.500 mil	level
Comprehensive Geriatric Education	\$4.500 mil	*	*
National Institutes of Health	\$30.084 bil	\$32.084 bil	+\$2.000 bil (+6.65%)
National Institute of Nursing Research	\$140.953 mil	\$146.485mil	+\$5.532 mil (+3.92%)

1 Source: Consolidated and Further Continuing Appropriations Act of 2015 [P.L. 113-235]. (2014) Accessed from: <https://www.congress.gov/bills/113th-congress/house-bill/83/actions>.

2 Source: Senate Amendment to H.R. 2029 report language for Labor, Health and Human Services, Education Appropriations bill. (2015). Retrieved from: <http://docs.house.gov/meetings/RU/RU00/20151216/104298/HMTG-114-RU00-20151216-SD009.pdf>.

* The Title VIII Comprehensive Geriatric Education program was combined into a broader HRSA Geriatrics Programs. See page 104 of report: <http://docs.house.gov/meetings/RU/RU00/20151216/104298/HMTG-114-RU00-20151216-SD009.pdf>.

Subcommittee Hears Title VIII Reauthorization Bill

The House Energy and Commerce Subcommittee on Health held a hearing December 9, 2015 examining "Legislation to Improve Health Care and Treatment," which included discussion and testimony on the Title VIII Nursing Workforce Reauthorization Act of 2015. APHON signed on to the [written testimony](#) submitted for the record.

APHON Joins in Concern over CDC Guidelines

APHON joined with members of the Patient Quality of Life Coalition in expressing [concern](#) about the Centers for Disease Control and Prevention's (CDC) Draft Guideline for Prescribing Opioids for Chronic Pain, 2016 (Guideline).

HRSA Updates NURSE Corps Loan Repayment and Scholarship Programs

The Health Resources and Services Administration (HRSA) announced additional site types eligible for the NURSE Corps Loan Repayment and Scholarship Programs. Eligible Nurse Corps Site Types in 2016 include:

- Critical Access Hospital (CAH)
- Disproportionate Share Hospital (DSH)
- Public Hospital
- Private Hospital
- Federally Qualified Health Center (FQHC)
- Indian Health Service Health Center
- Native Hawaiian Health Center
- Rural Health Clinic
- State or Local Public Health or Human Services Department
- Nurse Managed Health Clinic/Center
- Urgent Care Center
- Certified Community Behavioral Health Clinics (CCBHs)
- End Stage Renal Disease (ESRD) Dialysis Centers
- Ambulatory Surgical Center
- Residential Nursing Home*
- Home Health Agency
- Hospice Program

*Includes: skilled nursing facilities, transitional facilities, assisted living and group homes.

Registered nurses and advanced practice nurses currently employed at one of the site types listed above may be eligible to apply for the NURSE Corps Loan Repayment Program, which is scheduled to open in January 2016. For more information visit the [HRSA website](#).

Issues and Legislation of Interest

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

Access to Treatment

[S. 1883/H.R. 3381](#) *Childhood Cancer STAR Act*

Maximizes discovery, and accelerate development and availability, of promising childhood cancer treatments, and for other purposes.

Latest Senate Action: Referred to Health, Education, Labor, and Pensions (HELP) Committee

Latest House Action: Referred to Energy and Commerce Health Subcommittee

[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.

Latest Senate Action: Referred to Finance Committee

Latest House Action: Referred to Energy and Commerce Health Subcommittee

[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.

Latest Senate Action: Referred to Finance Committee

Latest House Action: Referred to Energy and Commerce Health Subcommittee

[H.R. 1537/S. 1878](#) *Advancing Hope Act of 2015*

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

Latest Senate Action: Referred to HELP Committee

Latest House Action: Referred to Energy and Commerce Health Subcommittee

[H.R. 3012](#) *Right to Try Act of 2015*

To authorize the use of unapproved medical products by patients diagnosed with a terminal illness in accordance with State law, and for other purposes.

Latest House Action: Referred to Judiciary Subcommittee on Crime, Terrorism, Homeland Security, and Investigations

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.

Latest Senate Action: Referred to Budget Committee

Latest House Action: Referred to Budget Committee

[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.

Latest House Action: Referred to Energy and Commerce Health Subcommittee

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

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

Latest House Action: Passed the House, Referred to Senate HELP Committee

[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.

Latest Senate Action: Referred to HELP Committee

Latest House Action: Referred to Energy and Commerce Health Subcommittee

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

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

Latest House Action: Referred to Energy and Commerce Health Subcommittee

[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.

Latest House Action: Referred to Energy and Commerce Health Subcommittee

[H.R. 2820](#) *the Stem Cell Therapeutic and Research Reauthorization Act*

Reauthorizes the Stem Cell Therapeutic and Research Act, which provides federal support for cord blood donation, a national bone marrow registry, and research essential to increasing patient access to transplants.

Latest House Action: Passed the House and referred to Senate HELP Committee

Other

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

Latest House Action: Referred to Energy and Commerce Health Subcommittee

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