



## 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. Please send your health policy and advocacy news to Jordan at [jwildermuth@aphon.org](mailto:jwildermuth@aphon.org).

### PQLC Lobby Day

**By: Bobbie Caraher, RN**

We embarked on our road trip to the “Hill...” nicknaming ourselves the “Jeep Cherokee Coalition” since our mode of transportation was one of our team member’s Jeep Cherokees.

In reality, we were four Duke Pediatric Blood and Marrow Transplant Nurses on our way to proudly take part in the Patient Quality of Life Coalition’s (PQLC) third annual lobby day in Washington, DC. The anticipation and excitement for this trip had been growing for many weeks, but we were also nervous because we would be telling our personal nursing stories to lawmakers. Our mission was to educate lawmakers about the importance of federal policy changes to improve access to high-quality palliative care through education and training, awareness, and research. Specifically, we would be asking Members of Congress to support the Palliative Care and Hospice Education and Training Act (PCHETA, H.R. 3119/S. 2748). We had participated in the preparation sessions provided by the Coalition and we rehearsed and discussed our stories that we wanted to tell. We were ready!

On the morning of June 21 we headed to the ‘Hill’ (using Uber for the first time)! In total, the Coalition brought together 64 advocates from 26 different states that met with 52 Congressional offices, including 10 meetings with the actual Member of Congress. We were separated into 10 groups, comprised of 5-6 people each with a designated team leader from the Coalition. The team leader helped us navigate our way to each meeting and introduced us to the staffers. They also provided us with support and helped relieve our anxiety, but it did not take long to get over the nervousness because everyone we spoke to in the offices listened attentively and we felt like we were making a difference.

Since lobby day, the Coalition can track at least 8 new, bipartisan cosponsors as a direct result of our efforts. This event was a great reminder of the very important work we are doing as a team of health care professionals. Moreover, we valued the opportunity to share with Congress our experiences as nurses and our patient’s stories. We will continue to do everything we can to ensure our patients and their families have access to high-quality

patient-centered care and will press on to get the PCHETA passed, so watch out for the “Jeep Cherokee Coalition” from Duke!

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## Through the Years- The Evolution of APHON Advocacy Efforts

**By: Jordan Wildermuth, Health Policy & Advocacy Manager**

APHON continues to celebrate its 40<sup>th</sup> anniversary and in that spirit APHON staff provided me with a couple copies of previous APHON newsletters from the 1990’s containing legislative updates. I thought that it would be fun to dissect those updates and compare them to the current legislative and regulatory landscape.

The June 1993 Legislative Update focused on President Bill Clinton’s Task Force on Health Reform headed by then First Lady, Hillary Clinton. The Task Force introduced a proposal dubbed “Hillarycare” that required consumers to become enrolled in a qualified health plan and mandated employers provide insurance coverage for their employees. Sound familiar?

The Clinton healthcare reform bill was over 1,000 pages and was viewed as complex, cumbersome, and full of red tape. Critics viewed the reform as limiting patient choice and driving up costs. “Hillarycare” did not pass Congress in 1994 and the issue of health care reform was not discussed seriously for another 15 years. In 2008, the Affordable Care Act came about and was met with the same criticisms as the Clinton proposal. While the criticisms remained the same, public perception of the health care delivery system had changed and there was more pressure to address rising health care costs and the rate of uninsured individuals. “Hillarycare” set the foundation for the reform that is continuing to be implemented today.

On a more operational note, the spring 1996 newsletter included a legislative update with suggestions for action. This is the first record of APHON organizing calls to action on legislative issues.

A special thank you to the authors of these updates, Joan Hunt, MA RN and Jill Brace O’Neill, MS RN CS PNP CPON®

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## 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 Tracking Chart](#).

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## Take Action on PCHETA and the Star Act

There are a limited number of days left in the legislative session so now is the time to make a strong push to help both the Palliative Care & Hospice Education and Training Act (PCHETA) and the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act make it out of the 114<sup>th</sup> Congress.

There are currently 245 cosponsors of the **STAR Act** in the [House](#) and 18 cosponsors in the [Senate](#). Help us reach more offices by taking action today:

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



There are currently 190 cosponsors of **PCHETA** in the [House](#) and 4 cosponsors in the [Senate](#). Help us reach more offices by taking action today:

- [Learn more](#) about PCHETA
- [Write your Senators and Representatives](#)

APHON has signed on to a PCHETA [letter of support](#) from the Patient Quality of Life Coalition (PQLC).

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## Take Action on the ACE Kids Acts

The Advancing Care for Exceptional Kids (ACE) Act (S. 298/H.R. 546) would create an organized system of health care delivery for children with medical complexities to ensure access across state lines. The legislation would specifically:

- Create nationally designated children’s hospitals networks that would employ national quality standards and coordinate care
- Include in the networks a full range of acute, post-acute and primary care providers, with children’s hospitals as anchors, and a focus on outpatient care.

Take action by [writing your Senators and Representatives](#)

The House Energy and Commerce Committee held a hearing on the ACE Kids Act on July 7, 2016. You can find a recording of the hearing as well as a copies of written testimony on the Energy and Commerce Committee’s [website](#).

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## Take Part in APHON's Lobby Day

APHON is hosting its first Lobby Day in Washington, DC on Tuesday, September 20, 2016. As an APHON member residing in close proximity to the DC area, you are invited to attend. This event will educate lawmakers on the importance of pediatric hematology/oncology nursing as well as advocate for Congressional support of 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). Participating in the September 20th event requires the following commitment from you:

- Register for the event by emailing [Jordan Wildermuth](#).
- Participate in pre-Lobby Day training, via webinar the week prior to the Lobby Day. During this training, APHON will provide you with additional details about the lobby day event, inform you of what our legislative “asks” will be during Hill meetings, and answer your questions.
- Be in Washington, DC from 9:00 am – 5:00 pm on Tuesday, September 20, 2016.

Please RSVP if you are interested or available to attend so that we can get an idea of how many people to expect. We will assist in scheduling your visit as well as providing you with materials and education prior to the event so that you are prepared for your visits.

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## APHON Supports BPCA/PREA Recommendations

APHON joined in support of [policy principles](#) to optimize the Best Pharmaceuticals for Children Act and the Pediatric Research Equity Act. The recommendations target potential FDA policy changes that would enhance pediatric cancer drug development.

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## APHON Supports VHA Proposed Rule

APHON submitted a [letter of support](#) to the Department of Veterans Affairs in response to the proposed rule allowing Advanced Practice Registered Nurses (APRN) to practice to the full extent of their education, training, and certification.

## Senate Introduces Title VIII Reauthorization Companion Bill

APHON joined with members of the Nursing Community in a [letter of support](#) of the Nursing Workforce Reauthorization Act of 2016. This is the Senate companion bill to the House's legislation that was introduced on June 10, 2015.

## Update on FY 2017 Appropriations Process

The House and the Senate Committees on Appropriations have both passed their FY 2017 spending bills and the next step will be for the full chambers to take up the bills. The House and Senate bills vary in the spending levels requested so they will need to be referred to Conference Committee to iron out the differences in each bill. It is unlikely that a budget deal will be able to be reached by September 30 (end of FY 2016) so it is expected that a Continuing Resolution will be passed to maintain current funding levels for FY 2017.

<b>Association of Pediatric Hematology/Oncology Nurses</b>						
<b>FY 2016 Labor-Health and Human Services (L.HHS) Appropriations</b>						
	FY 2016 Enacted	FY 2017 APHON Request	FY 2017 President's Request	FY 2017 House Committee Passed	FY 2017 Senate Committee Passed	FY 2017 Final
<b>Health Resources and Services Administration (HRSA)</b>						
<b>Funding Programs:</b>						
Advanced Education Nursing	\$64,581,000		\$64,581,000	\$64,581,000	\$64,581,000	
Nurse Education, Practice, and Retention	\$39,913,000		\$39,913,000	\$39,913,000	\$39,913,000	
Nursing Workforce Diversity	\$15,343,000		\$15,343,000	\$15,343,000	\$15,343,000	
Loan Repayment and Scholarship Program	\$83,135,000		\$83,135,000	\$83,135,000	\$83,135,000	
Comprehensive Geriatric Education	*		*			
Nursing Faculty Loan Program	\$26,500,000		\$26,500,000	\$26,500,000	\$26,500,000	
<b>Total Title VIII Nursing Programs</b>	<b>\$229,472,000</b>	<b>\$244,000,000</b>	<b>\$229,472,000</b>	<b>\$229,472,000</b>	<b>\$229,472,000</b>	
<b>Nurse Managed Clinics</b>						
<b>National Institutes of Health (NIH)</b>						
National Institute on Nursing Research (NINR)	\$146,485,000	\$157,000,000	\$145,912,000	\$150,000,000.00	\$151,500,000	
National Cancer Institute (NCI)	\$3,214,000,000		\$3,204,000,000	3,338,444,000	\$3,629,700,000	
Gabriella Miller Kids First Research Act	\$12,600,000		\$12,600,000	12,600,000	\$12,600,000	
<b>Cancer Moonshot Initiative</b>						
National Institute of Health (NIH)			\$720,000,000			
Food and Drug Administration (FDA)			\$25,000,000			

## State of the 21<sup>st</sup> Century Cures Act

The bipartisan 21<sup>st</sup> Century Cures Act was passed by the House of Representative in July by a vote of 344-77 (170 Republicans and 174 Democrats). Provisions of the bill include reform of the current standards and appropriations for biomedical research, an increase in funding for the National Institutes of Health and the Food and Drug Administration, and a reduction of the regulations on access to medical research and the testing processes of new drugs.

The Senate has been working on its version of the House bill, the Innovations for Healthier Americans Act, and has been taking a more piecemeal approach by holding committee hearings on individual sections of the legislation. A hearing held on March 9, 2016 included the passage of the Advancing Hope Act of 2015 ([S. 1878](#)) which reauthorizes the pediatric drug voucher program implemented through the Creating Hope Act.

There are disagreements between the House and the Senate on funding the package, but House Speaker Paul Ryan said that a vote on the deal is expected to take place at the earliest in September and at the latest during the lame duck session.

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## Cancer Moonshot Initiative

On June 29, 2016, the Vice President hosted a Cancer Moonshot Summit in Washington, D.C. which brought together more than 300 stakeholders to generate ideas about how individuals and organizations can better engage in the Moonshot Initiative, and come up with ideas for new collaborations and actions. Actions that are already being taken by Federal agencies to accelerate progress on the initiative include:

**Establishment of the FDA Oncology Center of Excellence:** New center will unite cancer product regulatory review to enhance coordination and leverage the combined skills and clinical expertise across FDA centers.

**Establishment of Fast-Track Review for Cancer Treatment-Related Patents:** This will allow any applicant to opt into an acceleration program for review of patent applications in select fields of cancer therapy.

**Making Clinical Research Trials More Accessible to Cancer Patients:** The National Cancer Institute is re-designing how patients and oncologists learn about and find information about cancer clinical trials which will include making cancer clinical data hosted on cancer.gov available through an application programming interface (API) for advocacy groups, academia, and others in the cancer ecosystem to access directly.

More information can be found on the [Cancer Moonshot webpage](#).

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