



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.

***Send your health policy and advocacy news to Jordan at jwildermuth@aphon.org.**

Health Policy & Advocacy Agenda

Find out what APHON's health policy priorities are by viewing the [2017 agenda](#).

Bill Tracker

Visit the [Legislative Action Center](#) to see a list of bills that APHON is tracking.

Health Reform Tracker

The UCSF/UC Hastings Consortium on Law, Science and Health Policy has put together a helpful [ACA Repeal and Replace Legislative Timeline 2017](#).

APHON Members Educate Policymakers on Palliative and Hospice Care



PQLC Scholarship Recipient and APHON Member, Jennifer Livingston with

**Jennifer Livingston, MSN RN CPON®
4K Hematology/Oncology RN IV/Chemo RN
Arkansas Children's Hospital**

On June 28, 2017 I had the opportunity to travel to Washington, D.C. with five other APHON members as part of the Patient Quality of Life Coalition Lobby Day to ask Members of Congress to support the Palliative Care and Hospice Education and Training Act. I was teamed up with Tonya Bauer (also from APHON- Kentucky), Rebecca Kirch (Director of PQLC), and Dr. Nicole Braccio (Policy Director for National Patient Advocate Foundation) - Rebecca and Nicole were our 'leaders' that helped us navigate Capitol Hill and the meetings. Our group was able to meet with staffers from the offices of Representative Bruce Westerman and Senator Tom Cotton, in addition to meeting with Senator John Boozman himself. All of the offices that we met with seemed interested in the bill, were interactive during our meeting time, and asked a lot of questions. Having the opportunity to actually speak with Senator

Rep. Bruce Westerman (R-AR)

Boozman was truly a pleasure, I felt it was an easier connection speaking directly to him. Working in pediatric hematology/oncology at Arkansas Children's Hospital, the only children's hospital in the state, I was able to provide the Members with personal experiences of ways that palliative care has touched children and their families on a very local/personal level. I was also able to share with them the lack of palliative care content in the education I received many years ago in my undergraduate work. I went on to explain how it would greatly help upcoming nurses and doctors to have this content in their educational track. More photos from PQLC Lobby Day:



APHON member Meredith Lahl with Sen. Sherrod Brown (D-OH)



APHON member Kaye Schmidt taking a break after meeting with the office of Senator John Cornyn (R-TX)



APHON member Lauri Linder poses in front of the office of Rep. Rob Bishop (R-UT)

APHON Lobby Day

Take part in APHON's Lobby Day in Washington, DC on Wednesday, October 11, 2017. All APHON members are invited to attend. This event will educate lawmakers on the importance of pediatric

hematology/oncology nursing as well as advocate for Congressional support pediatric hematology/oncology issues. Participating in the October 11th 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 – 4:00 pm on Wednesday, October 11, 2017.

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 visits as well as providing you with materials and education prior to the event so that you are prepared for your visits. If you have any questions about the day please reach out to Jordan Wildermuth at the email above or at 847-375-6736.

RACE Act Passes Congress

The Research to Accelerate Cures and Equity (RACE) for Children Act passed the House on July 12 as part of the FDA Reauthorization Act and on August 3, passed on the Senate floor as part of the FDA Reauthorization Act. Now, it's on to the President's desk for signature. Read a [press release](#) from one of the bill's lead sponsors, Congressman G.K. Butterfield (D-NC)

Take Action on the Deferment for Active Cancer Treatment Act

[Contact your Representative](#) and ask them to support the Deferment for Active Cancer Treatment Act (H.R. 2976) which allows for the deferment of certain student loans during a period in which a borrower is receiving treatment for cancer and 6 months after such period.

Take Action on the STAR Act

On February 3, 2017 Senators Jack Reed (D-RI), Shelley Moore Capito (R-WV), Chris Van Hollen (D-MD) and Johnny Isakson (R-GA) as well as Representatives Michael McCaul (R-TX), Jackie Speier (D-CA), Mike Kelly (R-PA) and G.K. Butterfield (D-NC) reintroduced the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act (H.R. 820/S. 292).

The Childhood Cancer STAR Act is the most comprehensive childhood cancer legislation ever taken up by Congress. It represents important bipartisan legislation designed to advance pediatric cancer research and child-focused cancer treatments, while also improving childhood cancer surveillance, and providing enhanced resources for survivors and those impacted by kids' cancers. For more information read the [press release](#) from the Alliance for Childhood Cancer. Here is how you can get involved:

[Contact](#) your Member of Congress and ask them to support the STAR Act.

Alliance for Childhood Cancer Mini Lobby Day - August 15

In an effort to attract more Republican Senate support, a mini Lobby Day was held on Capitol Hill on Tuesday, August 15. Senate targets included:

Lisa Murkowski (R-AK)	Joni Ernst (R-IA)	Bob Corker (R-TN)	Rob Portman (R-OH)
Deb Fischer (R-NE)	Pat Toomey (R-PA)	Dean Heller (R-NV)	Pat Roberts (R-KS)
Tim Scott (R-SC)	Cory Gardner (R-CO)	Ron Johnson (R-WI)	

There are currently 18 Republicans and 15 Democrats in the House that cosponsored the STAR Act last Congress but have not signed back on yet (despite repeated requests). Outreach is needed to these offices to ask why they have not signed back on. Here is the list:

McMorris Rodgers, Cathy (R-WA)	Collins, Chris (R-NY)	Reed, Tom (R-NY)	Murphy, Tim (R-PA)
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Dent, Charles (R-PA)	Bilirakis, Gus (R-FL)	Buchanan, Vern (R-FL)	Bucshon, Larry (R-IN)
Rokita, Todd (R-IN)	Burgess, Michael (R-TX)	Hudson, Richard (R-NC)	Meadows, Mark (R-NC)
Fortenberry, Jeff (R-NE)	Paulsen, Erik (R-MN)	Bishop, Mike (R-MI)	Crawford, Rick (R-AR)
Hill, French (R-AR)	Sanford, Mark (R-SC)	Schrader, Kurt (D-OR)	Ruppersberger, C.A. (D-MD)
Lee, Barbara (D-CA)	Cuellar, Henry (D-TX)	Doggett, Lloyd (D-TX)	Jackson Lee, Sheila (D-TX)
Johnson, Eddie Bernice (D-TX)	Castro, Joaquin (D-TX)	Lynch, Stephen (D-MA)	Neal, Richard (D-MA)
Adams, Alma (D-NC)	Meng, Grace (D-NY)	Meeks, Gregory (D-NY)	Esty, Elizabeth (D-CT)
Davis, Danny (D-IL)			



APHON Concerned with Proposed Changes to Medicaid

APHON joined other organizations in a [letter](#) to Senate leadership outlining concerns about potential changes to the fundamental structure and purpose of Medicaid.

APHON Supports Expanded Access Principles

As policymakers debate changes to the way in which unapproved therapies are accessed, APHON agrees that changes should adhere to certain [principles](#).

2017 Childhood Cancer Awareness Month Activities

Sept 13-14: Rally for Medical Research
 Sept 14: Congressional Childhood Cancer Caucus
 Sept 14: Alliance Luncheon and Art Show (call for exhibits below)
 Sept 14: Golden Toast
 Sept 16-17: Cure Fest

Calling all childhood cancer families! We invite you to submit artwork for the 3rd Annual Alliance for Childhood Cancer Art Exhibit. The exhibit will showcase the work of children with cancer, survivors, and siblings and will be featured on Capitol Hill immediately following the Congressional Childhood Cancer Summit in September. Find more information [here](#).

Spending Clears First Hurdle

The House Appropriations' Labor, Health, and Human Services Subcommittee passed their Fiscal Year 2018 spending bill which includes:

1. National Institutes for Health - \$35.2 billion (\$1.1 billion increase)
2. National Institute of Nursing Research - \$152.599 million (\$2.33 million increase)

3. National Cancer Institute – \$5.77 billion (\$82 million increase)
4. Cancer Moonshot - \$300 million (\$496 million request in 21st Century Cures Act)
5. Provision requiring NIH to reimburse grantee research institutions for facilities and administrative costs
6. Title VIII - \$83.135 million for NURSE Corps and \$128.067 million for Nursing Workforce Development (\$18.27 million decrease)

There is concern that the Title VIII funding does not delineate separate funding or how much funding for Advanced Nursing Education, Nursing Workforce Diversity, Nurse Faculty Loan Program, Nurse Education, Practice, Quality and Retention program or Comprehensive Geriatric. The Nursing Community sent letters to the full [House Appropriations Committee](#) and [Senate Appropriations Committee](#) expressing concern with the consolidation and cuts.

FDA Commits to Reducing Orphan Drug Backlog

The Food and Drug Administration (FDA) released a [strategic plan](#) to ensure timely review of orphan drug designation requests. The goals of the plan are as follows:

1. In 90 days, FDA will complete reviews of all orphan drug designation requests that are older than 120 days (the backlog) while maintaining consistent, scientifically rigorous reviews
2. After 90 days, 100 percent of all new orphan drug designation requests will receive a response by the agency within 90 days of receipt. FDA will adhere to this 90-day timeline going forward.

Specific to pediatrics, the Office of Orphan Products Development (OOPD) will collaborate with the Office of Pediatric Therapeutics (OPT) to jointly review rare pediatric disease designation requests. In these cases, OPT will conduct the pediatric review and OOPD will conduct the rare disease review. This policy began as of May 15, 2017.

Orphan status for drugs and biologics is defined as those intended for the safe and effective treatment, diagnosis or prevention of rare diseases/disorders that affect fewer than 200,000 people in the U.S., or that affect more than 200,000 persons but are not expected to recover the costs of developing and marketing a treatment drug. This initiative is vitally important for pediatrics because of the 30 million Americans affected by rare diseases and disorders, more than half are children.

FDA Launches Expanded Access Navigator

The Food and Drug Administration (FDA) has launched a new online tool called the [Expanded Access Navigator](#) to educate patients and physicians about the FDA's expanded access process including a directory where companies can submit public links to their expanded access policies, criteria used by companies to determine whether to make a drug available through expanded access, and contact information.

FDA to Host Pediatric Trial Design Workshop

On September 8, 2017, the Food and Drug Administration (FDA) is hosting a public workshop entitled "Pediatric Trial design and Modeling: Moving into the next decade". The purpose of this one day workshop is to:

1. Review the current best practices in designing pediatric drug development trials using the knowledge and tools available;
2. Discuss problems and potential solutions presently encountered with pediatric drug development trials;
3. Discuss strategies related to design and evaluation that have the best chance of facilitating and optimizing the use of pediatric drug development trials to achieve the labeling of products for pediatric indications.

More information can be found on the [FDA website](#).

National Academies of Science, Engineering and Medicine Releases Pain Management Study

National Academies of Science, Engineering and Medicine (NASEM) recently released [*Pain Management and the Opioid Epidemic: Balancing Societal and Individual Benefits and Risks of Prescription Opioid Use*](#) which provides a state of the science on pain research, care, and education and identifies actions the Food and Drug Administration and others can take to respond to the opioid epidemic.

Cancer Moonshot Funding Opportunities

The 21st Century Cures Act, which was signed into law in December 2016 made \$300 million available in Fiscal Year 2017 for the National Cancer Institute (NCI) to accelerate research efforts aligned with the Cancer Moonshot. The NCI has updated the [Cancer Moonshot webpage](#) to list all funding opportunity announcements aligned with the goals of the Moonshot.

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