



Pediatric Policy Council Update May 2018

The APS and SPR are members of the Pediatric Policy Council (PPC) which actively advocates for children and academic pediatrics at the federal level. APS representatives to the PPC are Drs. Scott C. Denne (incoming PPC Chair) and Jonathan M. Davis; Drs. Vivek Balasubramaniam and Shetal Shah represent the SPR.

The PPC also includes representatives from the Academic Pediatric Association (APA) and the Association of Medical School Pediatric Department Chairs (AMSPDC). The PPC is based in the Washington DC office of the American Academy of Pediatrics (AAP), who supplies staff and other support.

The latest advocacy developments are summarized by the PPC below.

PPC CAPITOL CONNECTION

May 25, 2018

What Matters Now in Washington:

- An initiative to coordinate pediatric research at NIH was announced earlier this month.
- Paul Chung, MD, MS, was honored at PAS for his outstanding contributions to the PPC during his four-year tenure as chair.
- NICHD is funding a multi-site research capacity building grant focused on pediatric firearm injury prevention.
- Congress completed the Fiscal Year (FY) 2018 appropriations process with the passage of a \$1.3 trillion spending bill, allowing work on a FY 2019 spending bill to commence.
- Public enrollment in the All of Us Research Program opened in May as NIH works to enroll 1 million Americans.
- The Trump administration is considering an additional six-month delay to the updated Common Rule governing human subjects research.

NICHD Director Announces Trans-NIH Initiative to Coordinate Pediatric

Research. During a talk on May 6 at the Pediatric Academic Societies (PAS) Meeting, Diana Bianchi, MD, Director of the National Institute of Child Health and Human Development (NICHD), announced for the first time the formation of a new initiative to better coordinate research across the National Institutes of Health (NIH). NIH Director Francis Collins, MD, PhD, explained at a congressional hearing just two weeks later that the purpose of the initiative is to "see whether we could come up with a more coordinated strategic plan for defining where are the greatest priorities in pediatric research and how we can work together." The Trans-NIH Pediatric Research Consortium will harmonize efforts in child health research across the 27 Institutes and Centers at NIH and identify gaps and opportunities for collaboration. The effort will also serve to enhance communication between

NIH, advocacy groups, and Capitol Hill, encourage senior pediatric researchers to serve on review panels, and work across NIH to support training to grow the pediatric workforce. Senior staff from all 27 Institutes and Centers have already been selected to serve on the consortium.

PPC Holds Policy Sessions at PAS, Honors Paul Chung for Service as PPC Chair.

Paul Chung, MD, MS, outgoing Chair of the Pediatric Policy Council (PPC) was honored at this year's PPC State-of-the-Art Plenary at the Pediatric Academic Societies Meeting in Toronto. Scott Rivkees, MD, PPC representative from the Association of Medical School Pediatric Department Chairs, presented Dr. Chung with a plaque in recognition of his four years of leadership at the helm of the PPC and his commitment to improving the lives of children through public policy. The state-of-the-art plenary featured presentations from leading child health and policy experts on the impacts of the opioid epidemic on children and families and related policy solutions. The PPC also held its annual Legislative Breakfast, which featured remarks from Donna Victoria, a Washington-based pollster, on the upcoming midterm elections and the ways that medical and scientific experts are leveraging their expertise to engage in politics.

NIH Funds Research Consortium to Address Firearm Deaths Among Children and Adolescents. The University of Michigan was [recently awarded \\$5 million by NICHD to lead a research capacity building grant to address firearm deaths among children](#). The grant will involve 20 researchers at 12 universities and health systems across the country. The research initiative, known as the Firearm-safety Among Children & Teens Consortium (FACTS), will focus on preventable firearm injuries among children and adolescents, including unintentional injury by toddlers who find a gun, self-inflicted harm by suicidal adolescents, and school shootings. Researchers in the consortium will begin by creating a research agenda for the field of firearm injury specific to pediatrics, which will be published this fall. This will be followed by completion of five small projects in some of the areas in the firearm injury field with an eye toward generating preliminary data that can be expanded into large investigations, as well as the creation of a data archive on childhood firearm injury. The FACTS consortium will also train new researchers focused on firearm injury prevention research.

\$1.3 Trillion Omnibus Spending Bill Enacted, Including Major Funding Bumps for Child Health Programs. On March 23, President Trump signed into law a [FY 2018 omnibus spending bill that funds the government through September 30](#), averting what would have been the third government shutdown of 2018. The spending agreement, [negotiated between congressional Republicans and Democrats](#), included large funding increases for domestic priorities and defense spending. Additional spending authority unlocked by [February's bipartisan budget deal](#), which increased defense and non-defense discretionary spending caps, enabled appropriators to direct more funds into a number of programs than initially expected. The [National Institutes of Health \(NIH\) received a \\$3 billion increase](#) over Fiscal Year (FY) 2017, following two years of \$2 billion increases for NIH and at \$1 billion more than the research community had sought. Additionally, the Children's Hospital Graduate Medical Education (CHGME) program got a \$15 million funding boost, while the Emergency Medical Services for Children (EMSC) program saw a funding increase of \$2.17 million. Congress will now begin work on a FY 2019 appropriations bill, which will need to be completed before the October 1 start of the next fiscal year.

—Gun Violence Research Addressed But Not Funded. In the wake of the Parkland shooting, a dialogue continues to evolve around gun violence prevention measures. Of particular bipartisan appeal is funding for the Centers for Disease Control and Prevention (CDC) to [conduct research into the public health effects of gun violence](#). While many in the gun violence prevention space have been interested in advancing this cause for some time to better inform future policymaking, the ask has been a major focus of advocates in recent months. Just one day after Parkland, Health and Human Services Secretary Alex Azar [stated in a congressional hearing](#) that he believed the federal government was not barred from conducting public health research into gun violence; the 1996 Dickey Amendment prevents the CDC from advocating or promoting gun control, which has essentially halted all federally funded gun violence research for more than 20 years. Many were hoping for the repeal of the Dickey Amendment in the omnibus. While Congress did not do this, [it did include language](#) indicating that Secretary Azar felt the federal government has the authority to fund gun violence research, a promising but small step forward. [More importantly, despite the apparent approval from Congress of such research, appropriators](#)

included no additional funding for gun violence research, without which the federal government will be unable to fund studies. Advocates continue to push for sustained funding to ensure that this long-dormant research area can be rebuilt.

—Spending Bill Fails to Address Insurance, Immigration Priorities. Despite the spending bill's massive scope, the package failed to address two major outstanding legislative items: insurance market stabilization and a legislative fix for the Deferred Action for Childhood Arrivals (DACA) program. Since congressional Republicans' last attempt to repeal and replace the Affordable Care Act (ACA) using the fast-track budget reconciliation process failed in late September, talks have been ongoing around a narrowly focused bill to stabilize shaky individual insurance markets across the country. Discussions commenced in both chambers, but Sens. Lamar Alexander (R-Tenn.) and Patty Murray (D-Wash.), chairman and ranking member of the Senate Health, Education, Labor, and Pensions Committee respectively and long known as bipartisan dealmakers, emerged with the most serious proposal to soothe individual insurance markets. The proposal largely centered around giving states increased flexibility on ACA rules and providing additional funding for reinsurance. However, disagreements over restrictions on abortion funding ultimately prevented the proposal from being included in the omnibus. Similarly, congressional leaders were unable to come to an agreement around a legislative fix for DACA in exchange for increased funding for border security, despite President Trump's unexpected last-minute threat to veto the entire spending package for failing to address the issue. While work on both issues continues, the omnibus is largely expected to be one of the last major legislative vehicles to move this year before the midterm election cycle begins in earnest, which will make action on either of these issues challenging.

All Of Us research Program Launches. On May 6, the All of Us Research Program officially opened for enrollment to everyone living in the United States, ages 18 and older. The research program aims to enroll 1 million Americans in order to advance the promise of precision medicine and transform health care. Precision medicine is an emerging approach to disease treatment that takes into account differences in individuals' lifestyles, environments, and biological makeup to create targeted prevention and treatment interventions. While All of Us is currently only enrolling those above the age of 18, NIH has plans to enroll children in All of Us in the future, though the timeline is not currently known.

HHS Contemplates Delay of Common Rule. The Department of Health and Human Services (HHS) and other federal agencies issued a proposed rule in April to delay changes to the so-called Common Rule by an additional six months. Also known as the Federal Policy for the Protection of Human Subjects, the Common Rule governs research performed on human subjects across the federal government. The Obama administration finalized an update to the decades-old Common Rule in the final days of President Obama's term. The Trump administration has acted several times since to delay the implementation of the updated Common Rule, partially in response to requests from some in the research community for additional time to comply. If the proposed rule moves forward, the updated Common Rule would go into effect in January 2019

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