



Pediatric Policy Council Update

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. DeWayne Pursley and Jonathan M. Davis; Drs. Joyce Javier 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

January 9, 2019

What Matters Now in Washington:

- The federal government shut down in December following an impasse over funding for a border wall and is set to become one of the longest lapses in federal appropriations in U.S. history. [More...](#)
- Democrats took control of the House of Representatives on January 3 as a new Congress was seated. [More...](#)
- Two migrant children have died in Customs and Border Protection custody in the last month, leading to renewed calls for oversight of federal immigration enforcement efforts. [More...](#)
- NIH Director Francis Collins affirmed the importance of fetal tissue research in further scientific knowledge, calling it the “gold standard” in certain types of research. [More...](#)
- Congress finished work on some child health priorities prior to the end of the year, but work on others will have to begin anew this year. [More...](#)
- NICHD released a request for information to inform the development of its strategic plan. [More...](#)

MANY FEDERAL AGENCIES REMAIN SHUTTERED AS GOVERNMENT SHUTDOWN STRETCHES INTO 2019.

In early December, Congress passed a short-term government funding bill to allow for extra time to reach a government funding agreement following the death

of former President George H. W. Bush. On December 21, the [clock ran out with no agreement in sight](#), and Congress headed home to observe the Christmas holiday, ensnared in a deep-seated dispute over funding for President Trump's proposed border wall. [The result](#): hundreds of thousands of federal employees were sent home and many others deemed essential were instructed to continue working without pay.

—Most Federal Health Programs Will Remain Open But Other Key Parts of Government Are Closed. The Department of Health and Human Services (HHS) was one part of the federal government already funded in full through the end of the current fiscal year, meaning it's [business as usual for most of the federal government's health operations](#) like the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Centers for Medicare and Medicaid Services (CMS). However, numerous federal agencies remain closed, from the Environmental Protection Agency (EPA) to the National Park Service. Additionally, some parts of HHS are impacted by the government shutdown. Due to a quirk of the congressional appropriations process, the Food and Drug Administration (FDA) is funded with the Department of Agriculture even though it formally resides within HHS, causing roughly [40 percent of staff at FDA to be furloughed](#). Similarly, the Indian Health Service (IHS), which is also a part of the Department of Health and Human Services, is funded with the Department of the Interior, meaning frontline health care workers employed by [IHS](#) will work without pay.

—No End in Sight as Stalemate Drags On. As Congress returned to Washington for a new year, a breakthrough in negotiations has continued to elude the leaders of the two major parties. Democrats, under newly elected House Speaker Nancy Pelosi (D-Calif.), [passed two bills to reopen the government](#), one to fund most federal agencies through the end of the year and the other to provide a short-term funding extension for the Department of Homeland Security, the agency that would be the recipient of any border wall funding. However, Senate Republicans and President Trump remain uninterested in any plan that does not provide wall funding, even as the shutdown drags into [one of the longest running in recent history](#).

NANCY PELOSI ELECTED HOUSE SPEAKER AS NEW CONGRESS IS SEATED. On January 3, the House of Representatives [elected Rep. Nancy Pelosi \(D-Calif.\) speaker of the House](#), marking a triumphant return to the speaker's podium for the first female speaker of the House in U.S. history after last holding the gavel in 2011. The new Congress features a [record number of women](#)—more than 100—and a more religiously and racially diverse set of representatives. In total, [Democrats hold 235 seats to Republicans' 199](#). Meanwhile, the Senate will have [53 Republicans to 47 Democrats](#), which includes two independents who caucus with the Democratic senators. The new Congress represents a return to divided government, which is set to usher in new political dynamics as President Trump and congressional Republicans are forced to work with newly empowered House Democrats.

RENEWED CALLS FOR OVERSIGHT AFTER IMMIGRANT CHILDREN DIE IN CBP CUSTODY. [Pediatricians](#) and Democratic members of Congress are calling for renewed oversight of federal immigration authorities after two migrant children died in Customs and Border Protection (CBP) custody just weeks apart. Seven-year-old [Jakelin Caal Maquin died](#) on December 7 after being apprehended by CBP officials for crossing the U.S. border from Mexico illegally. She had reportedly not eaten or consumed water for several days leading to her death. Weeks later, 8-year-old [Felipe Alonzo-Gomez died in CBP custody](#) after being taken to the hospital and diagnosed with a cold. Both children were apprehended with their fathers after making the journey to the United States from Guatemala. In the wake of Jakelin Caal Maquin's death in early December, the [Pediatric Policy Council joined other medical and mental health provider organizations](#) to call on the Department of Homeland Security (DHS) and CBP to

conduct a full, transparent, and public investigation. Additionally, Democratic lawmakers have called for [oversight hearings and potential legislative action](#) to address concerning conditions for migrants in federal government custody. In the wake of Alonzo-Gomez's death, the [Department of Homeland Security \(DHS\) announced immediate medical screenings for all migrant children](#) at the southern U.S. border, but a new Democratic House is likely to push for far greater oversight and additional protections for children.

COLLINS DEFENDS USE OF FETAL TISSUE AS HHS REVIEW OF THE PRACTICE CONTINUES. National Institutes of Health (NIH) Director [Francis Collins, MD, PhD, publicly defended the use of human fetal tissue in biomedical research](#) in December, noting that the practice would continue to be a mainstay and indicating that there is strong evidence of scientific benefit from fetal tissue research. He also indicated that such research can be done within an ethical framework. Collins's comments caused an [outcry among anti-abortion activists](#), who immediately called for his ouster over views they see as inconsistent with the Trump administration's "pro-life" bent. The comments come as an ongoing [review of federal funding of fetal tissue research](#) continues at the Department of Health and Human Services (HHS), which has led to [confusion](#) among some NIH-funded researchers using fetal tissue about whether they will be able to continue their work. As part of the review, NIH held a workshop in December to convene experts and understand whether alternatives to the use of fetal tissue exist in biomedical research. The group ultimately [concluded that fetal tissue is the "gold standard"](#) for certain studies and that any alternatives must be validated against research using fetal tissue. No final decisions on future funding of fetal tissue research by the federal government have been made.

CHILD HEALTH PRIORITIES MOVE IN FINAL DAYS OF 115TH CONGRESS. As 2018 came to a close, Congress passed several child health priorities. The Juvenile Justice Reform Act was signed into law, reauthorizing and modernizing the Juvenile Justice and Delinquency Prevention Act. This bill will bring about important reforms in the juvenile justice system with a focus on alternatives to detention for youth and improved protections for youth who do enter the juvenile justice system. Congress also passed the Prematurity Research Expansion and Education for Mothers who deliver Infants Early (PREEMIE) Reauthorization Act to expand research into premature births, as well as bills to improve research into congenital heart defects and sickle cell disease. All of these bills were signed into law. Unfortunately, several child health priorities were not passed and signed into law during the 115th Congress, meaning these bills will have to be reintroduced this year and moved through the legislative process anew. These bills include a reauthorization of the Emergency Medical Services for Children program, a major reform to the way the Food and Drug Administration (FDA) regulates over-the-counter (OTC) drugs that would make it easier for FDA to protect child health based on the latest data, and a reauthorization of the Pandemic All-Hazards Preparedness Act.

NICHD STRATEGIC PLAN RELEASES RFI. The National Institute of Child Health and Human Development (NICHD) announced a request for information (RFI) to inform its strategic planning process. The RFI seeks feedback regarding the scientific themes, goals, and opportunities NICHD is considering for the new strategic plan. [The RFI is available online and responses will be accepted through February 15.](#)